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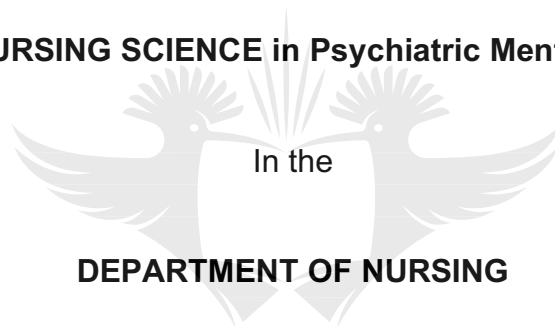
**THE LIVED EXPERIENCE OF FAMILY MEMBERS CARING FOR A  
RELATIVE WITH MENTAL ILLNESS**

**By**

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Minor Dissertation submitted as partial fulfilment for the degree

**MASTERS IN NURSING SCIENCE in Psychiatric Mental Health Nursing**



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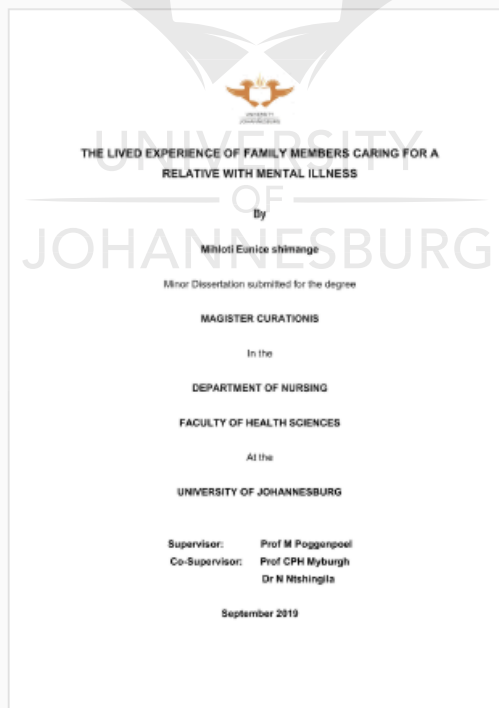


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## DEDICATION

I dedicate this study to my family as a whole especially my four kids namely: Muyimeri Clement Nkuna, Vuthlari Daniel Shimange, Ndzalama Derrick Shimange and Matimu Nhlengani Shimange whom I left under the care of the nanny and my mother while travelling to Johannesburg to study towards this degree.

May this research study encourage them to study hard and attain whatever they desire in life academically and they also remember that where there is a will there is always a way.



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## ABSTRACT

Mental illness may cause a variety of psychosocial problems such as decreased quality of life for the patient's family members, as well as increased social distance for the relative and the family caring for a relative with mental illness. The family members caring for a relative with mental illness reported that they felt stigmatised as a result of their association with the person with mental illness. It seems that this burden of stigmatisation is more severe in low-income countries. It is aggravated by poverty and family members consequently suffer psychologically and socially due to living with or caring for a relative with mental illness.

The purpose of this study was to explore and describe the lived experiences of family members caring for a relative with mental illness in Giyani, Limpopo province, and to make specific recommendations to facilitate the mental health of family members caring for a relative with mental illness.

A qualitative, exploratory, descriptive and contextual research design was utilised in this study. The study took place in two phases. In Phase 1, a total of eight participants were interviewed. Data were collected by means of conducting individual, in-depth, phenomenological interviews, observations and field notes. The following research question was asked to individual participants: "What is it like caring for a relative with mental illness?" Data were analysed utilising open coding and an independent coder. In phase 2, specific recommendations were described based on the results of phase 1

The results of the study revealed the following:

- Theme 1: Family members experienced being alert about the safety of their relative with mental illness.
- Theme 2: Family members experienced that their relative was not mentally stable as evidenced by erratic behaviour.

- Theme 3: Family members experienced challenges caring for a relative with mental illness.
- Theme 4: Family members experienced coping strategies in caring for a relative with mental illness.

Family members caring for a relative with mental illness were of the opinion that they were at risk of being injured or killed by their violent and aggressive relative with mental illness, and as such, families lived in fear. The family understood that their relatives with mental illness were mentally unstable as evidenced by their behaviour. The behaviour of the relative with mental illness did not only affect the family but also other people, including the community in which they lived. Family members experienced challenges when caring for a relative with mental illness. Challenges included financial challenges and caring challenges, which resulted in feeling obliged to care and exhaustion as well as rumours which were spread by the community. Family members experienced coping strategies in caring for a relative with mental illness. Family members showed a narrow range of coping strategies when dealing with their relative's disruptive behaviours. They revealed that they prayed in order to cope with the situation of caring for a relative with mental illness.

Specific recommendations were formulated to facilitate the mental health of family members caring for a relative with mental illness in Giyani, Limpopo province. These specific recommendations focused on reducing the burden of caring for a relative with mental illness by involving the government and healthcare providers in caring for relatives with mental illness.



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# CHAPTER 1

## INTRODUCTION AND OVERVIEW

Mental illness may cause a variety of psychosocial problems such as decreased quality of life for the patient's family members, as well as an increased social distance for the relative and the family members caring for a relative with mental illness (Ae-Ngibise, Korley, Asante & Owusu-Agyei, 2015:6). The family members caring for a relative with mental illness report that they experience being stigmatised as a result of their association with the relative with mental illness. It is expected that this burden is more severe in low-income countries as it is aggravated by poverty; consequently, family members suffer psychologically and socially due to caring for a relative with mental illness (Ae-Ngibise et al., 2015:5).

In this chapter, the researcher discussed the background and rationale of the study, the problem statement was clearly explained with the subsequent research question as well as study objectives. The paradigmatic perspectives and relevant concepts that was used throughout the study were defined, and the researcher also explained the significance of the study. The research design and method was presented to ensure trustworthiness and ethical consideration. These aspects was discussed in greater detail in Chapter 2.

### 1.1 BACKGROUND AND RATIONALE

Globally, it is estimated that 450 million people are affected by mental illness at any given time. These include 121 million people with depression, 24 million with schizophrenia, and 37 million with dementia. Mental illness accounted for 12.3% of the global burden of disease in 2001, and it is estimated that by 2020 depressive disorders will be the second-highest cause of disability (World Health Organisation (WHO), 2011:42). Monyaloue, Mvandaba, du Plessis and Koen (2014:131) state that the burden of caring for relatives with mental illness falls on the family members who provide all the necessary support to these individuals. People with mental illness often cause distress among their family members and most are overwhelmed by the patients' symptoms (Monyaloue et al., 2014:131). According to evidence, some developing



countries show a higher prevalence of psychiatric patients living with family members as their primary caregivers (WHO, 2011:42). In Uganda, for example, the Ugandan National Health Statistics (UNHS) of 2005/2006 report that of all households with disabled members, 58% had at least one person with a mental disorder. The statement was supported by Ae-Ngibise et al., (2015:6), who agree that relatives with mental illness normally consult traditional healers and the reasons for not attending health facilities still remains unclear. Most family members believe that mental illness is not a disease but a curse, which may be among their reasons for not seeking health care.

Mental illness may cause a variety of psychosocial problems such as decreased quality of life for the patient's family members, as well as increased social distance for the patient and the family caring for the patient (Iseselo, Kajula & Yayha-Malima, 2016:7). The family members caring for a relative with mental illness report to be experiencing stigma as a result of their association with individuals with mental illness. Many studies in developed countries have focused on the burden encountered by family members with little attention to psychosocial impacts and coping skills when caring for the patient (Ae-Ngibise et al., 2015:6-7). Coping differs from one family to another for a variety of reasons. In developed countries family coping is emphasised as a key concept for the study of adaptation (Iseselo et al., 2016:3). Family members caring for a relative with mental illness usually shoulder the greatest part of the burden of caring for their relative.

Between 70% and 93% of outpatients live with their families in the United States of America (USA) and the People's Republic of China (Iseselo et al., 2016:3). Spaniol, Zipple, Lockwood and Streda (2016:345) state that families act as caregivers. Family members caring for a relative with mental illness support other families with similar problems, teach and educate other consumers and the public at large, participate in research, and advocate improved services both for the individual and for patients in general. Providing continued care and support for people with mental illness is demanding and challenging, according to Monyaloue et al., (2014:02). There is evidence from around the world that family members are scantily supported to provide the care required by relatives with mental illness. This seems to be because of community attitudes and beliefs, frequently directed at family members caring for relatives with mental illness (Gale & Marshall-Luccette, 2012:4).

A study conducted across Europe revealed that caregiver burden in schizophrenia was high across England, Denmark, The Netherlands, Italy and Spain (WHO, 2012: 43). Monyaloue et al., (2014:131) are of the opinion that providing continued care and support for relatives with mental illness is demanding and challenging. Family members often become frustrated, stranded, overburdened and exhausted caring for their relatives. Family members may experience a substantial burden on their emotional and social integrity, combined with diminished psychological well-being, as seen in a study in New South Wales, Australia (Wilson, Cruickshank & Lea, 2012:4). Caring for a person with mental illness can be an overwhelming, challenging and distressing experience. Monyaloue et al., (2014:3) found that family members are forced to relinquish control of their everyday life; family members lose their energy and cannot manage everyday life; family members are unstable; and emotions influence the atmosphere negatively. Some even periodically live in seclusion.

According to Priestley and McPherson (2016:128-145), family members caring for a relative with mental illness require professional support for their own mental health needs. Stuart (2014:148) states that when a loved one is stricken with mental illness, every member of the family experiences the pain. He also indicates that this happens whether the relative with mental illness is one's brother, sister, mother, father, son, daughter, grandchild or grandparent; the same suffering is shared, and there are numerous experiences that confuse or frightens one. Furthermore, this also has a negative impact on family members who have chosen not to help the caregiver. Family members who decide to put their own needs ahead of the needs of their relatives with mental illness end up feeling guilty, ashamed, or depressed.

Iseselo et al., (2016:148) add that family members do not receive adequate, pertinent information about mental illness or effective support from mental health professionals. As a consequence, family members experience that their attempt to care is not supported by the healthcare system. In addition, family members frequently feel marginalised and undervalued, and believe that the impact of mental illness on them as carers has not been recognised; they might feel 'invisible' to medical services. It is thus clear that family members caring for a relative with mental illness might find it difficult to cope.

According to Stuart (2014:148), it seems that family members have no knowledge of how to handle a relative with mental illness. In addition, mental healthcare services designated to provide mental health care, and where people with mental illness attend follow-up appointments, appear not to have a formal support system for these families (Monyaloue et al., 2014:04). It is thus unclear how these families cope. Iseselo et al., (2016:07) also mention how family members caring for relatives with mental illness use strengths such as positive thinking and knowledge, behavioural coping strategies and crying as an emotional release. It is suggested that future studies need to focus on the strengths of family members to devise feasible interventions or strategies to lessen economic, social, psychological and emotional burdens for family members and carers.

The Mental Health Care Act, 17 (Act no.17 of 2002), refers to patients living with mental illness as mental health care users (MHCUs) and stipulates the conditions of the provision of care, treatment and rehabilitation for relatives with a mental illness. In terms of the the Mental Health Care Act, 17 (Act no.17 of 2002), the person, human dignity and privacy of every MHCUs must be respected. This is supported by Uys and Middleton (2016:430), who say that family intervention is the imported milieu for the treatment and rehabilitation of patients living with mental illness.

## **1.2 PROBLEM STATEMENT**

Most family members caring for a relative with mental illness are overburdened by their caregiving role. Through observation and conversations with family members caring for a relative with mental illness who were admitted in the psychiatric unit where the researcher worked in Limpopo province, she became aware that they find it difficult and stressful to take care of their relatives with mental illness. The family members caring for a relative with mental illness usually shoulder the greatest part of the burden in caring for their relative. Between 70% and 93% of outpatients live with their families in the USA and the Peoples' Republic of China (Iseselo et al., 2016:2), and little is known about the challenges they are facing in Limpopo province. The researcher thus found it necessary to conduct this study in a Limpopo psychiatric hospital since there is a real need to understand the lived experiences of these family members caring for a relative with mental illness.

The following research questions were posed:

- What are the lived experiences of family members caring for a relative with mental illness?
- What can be done to facilitate the mental health of family members caring for a relative with mental illness?

### **1.3 RESEARCH PURPOSE AND OBJECTIVES**

The purpose of this study was to understand the lived experiences of family members caring for a relative with mental illness, and to describe specific recommendations to facilitate the mental health of the family members caring for a relative with mental illness in Giyani, Limpopo province.

The research objectives were:

- to explore and describe the lived experiences of family members caring for a relative with mental illness in Giyani, Limpopo province; and
- to describe specific recommendations to facilitate the mental health of family members caring for a relative with mental illness.

### **1.4 PARADIGMATIC PERSPECTIVES**

Neumann (2014:94) describes a paradigm as a whole system of thinking. In this sense, the paradigm refers to the established research tradition in a particular discipline or a philosophical framework. This is also supported by Babbie and Mouton (2011:645), who define a paradigm as a “model or framework for observation and understanding, which shapes both what people see and how people understand it”. Lincoln and Guba (2013:85) consider a paradigm to be the net that contains the researcher’s epistemological, ontological and methodological premises. Paradigmatic perspectives in this study were based on the assumptions applicable to the research domain that a phenomenon occurs only when there is a person who experiences the phenomenon and the experience must be described (Monyaloue et al., 2014:02).

Next, the researcher discusses the meta-theoretical, theoretical and methodological assumptions of this study.

#### **1.4.1 Meta-theoretical assumptions**

Meta-theoretical assumptions, according to the University of Johannesburg (2017:4), refer to the researcher's view of a person and society. It provides a framework in which the theoretical assumptions are formulated. The assumptions of the Theory for Health Promotion in Nursing (University of Johannesburg, 2017:4-12) were used to define the concepts 'person', 'environment', 'psychiatric nursing', and 'mental health'.

##### **1.4.1.1 Person**

In the Theory for Health Promotion in Nursing (University of Johannesburg, 2017:5), a 'person' is defined as a whole being who embodies dimensions of body, mind and spirit. The person functions in an integrated, interactive manner with the environment, which includes the internal and external environment. The body includes all anatomical structures and physiological (biological) processes pertaining to the individual, family group and community. The psyche or soul includes all the intellectual, emotional and volitional processes of the individual. The spirit is the part of a person that reflects his or her relationship with God and others, and how they interact. In the context of the Theory for Health Promotion in Nursing (University of Johannesburg, 2017:5), the family members, as well as their relatives with mental illness, are viewed as a whole person functioning in an integrated manner with the environment.

##### **1.4.1.2 Environment**

According to the Theory for Health Promotion in Nursing (University of Johannesburg, 2017:6), the internal environment consists of the body, mind and spirit, and the external environment consists of the physical, social and spiritual dimensions. It is assumed that the lived experiences of family members caring for relatives with mental illness have a potential effect on the interactive processes of the family members' internal and external environment.

### **1.4.1.3 Mental health**

Uys and Middleton (2016:753) define 'mental health' as a state of being in which a person is simultaneously successful at working, loving and resolving conflicts by coping and adjusting to the recurrent stresses of everyday living. This statement does not mean that a mentally healthy person has no problems; the person might at certain times experience severe distress but is generally able to cope with the distress. Mental health is a dynamic interactive process in the patient with mental illness's environment. According to the Theory for Health Promotion in Nursing (University of Johannesburg, 2017:5), this interaction contributes to or interferes with the promotion of health and reflects the relative health status of the patient. Interaction is defined as a mutual, purposeful involvement between the family members and their relatives with mental illness. The therapeutic relationship forms the basis of family interventions.

In this study, it is assumed that the quality of interaction between the family members and their relative with mental illness plays a major role in the mental health of both the family members and their relative with mental illness. This is also supported by Stuart (2014:166), who indicated that mental health is a successful performance of mental functioning, resulting in productive activities, fulfilling relationships with other people, and the ability to adapt to change and cope with challenges. Mental health is essential to personal well-being, family and interpersonal relationships, and the ability to contribute to the community or society.

### **1.4.1.4 Psychiatric nursing**

According to Uys and Middleton (2016:755), psychiatric nursing is an interactive process. As primary caregivers, the family members facilitate the promotion of mental health through the mobilisation of resources. It is assumed that the family members' ability to mobilise resources in the internal and external environment is related to the promotion of the mental health of their relative with mental illness at home. Stuart (2014:6) defines 'psychiatric mental health nursing' as

"a specialized area of nursing practice committed to promoting mental health through the assessment, diagnosis, and treatment of human responses to mental health

problems and psychiatric disorders. Psychiatric-Mental Health Nursing employs a purposeful use of self as its art and a wide range of nursing, psychosocial, and neurobiological theories and research evidence as its science.”

In this study, a psychiatric nurse refers to a qualified professional nurse working in a psychiatric hospital who is caring for people with mental illness.

#### **1.4.2 Theoretical assumptions**

Theoretical assumptions are testable and provide epistemic assumptions about the field of research which form part of the existing theory of the family and related discipline. In the Theory for Health Promotion in Nursing (University of Johannesburg, 2017:8), it is stated that theoretical assumptions give form to the hypothesis or control theoretical statements of the research, and form the framework for the epistemic statement in the research. In this study, the researcher entered the research field with an open mind. She utilised bracketing to discard all preconceived ideas and beliefs to explore and describe the lived experiences of family members caring for a relative with mental illness.

#### **1.4.3 Theoretical definition of concepts**

The theoretical definitions of concepts used in this study are presented next.

##### **1.4.3.1 Lived experience**

Creswell (2014:126) defines ‘lived experiences’ in phenomenological research as a way of describing the meaning of a concept or a phenomenon experienced by family members. According to Van-Manen (2016:10), lived experiences refer to a representation of the experiences and choices of a given person, and the knowledge they gain from these experiences and choices. In this study, a lived experience refers to a description of the meaning of a concept or phenomenon experienced by family members caring for a relative with mental illness.

### **1.4.3.2 Mental illness**

Mental illness is a condition that affects a person's thinking, feeling or mood. Such conditions may affect someone's ability to relate to others and function each day. Each person will have different experiences – even people with the same condition (National Alliance on Mental Illness, 2013:5). According to Uys and Middleton (2016:753), mental illness, which is also referred to as 'mental disorder', is defined as a clinically significant behavioural or psychological syndrome or pattern that occurs within a person and it is associated with distress or disability. 'Mental illness' is also defined by Townsend (2014:783) as maladaptive responses to stressors from the internal or external environment, evidenced by thoughts, feelings, and behaviours that are incongruent with the local and cultural norms, and interfere with the individual's social, occupational, and/or physical functioning. In this study, mental illness refers to

### **1.4.3.3 Family member**

'Family member' is defined by Stuart (2014:138) as those people who, by birth, adoption, marriage or declared commitment share deep, personal connections and are mutually entitled to receive, and are obligated to provide, support; especially in times of need. A family member refers to any individual, such as a spouse, any descendants – whether natural or adopted – and the beneficial interests which are owned by any of such individuals (Oxford Dictionary, 2018a:835; Clark, 2014:7). In this study, family members refer to the members of the family who are providing emotional and psychosocial support to their relative with mental illness.

### **1.4.3.4 Relative**

A relative is defined as the person who is part of one's family. It can either be a parent, sibling, uncles, aunts, grandparents, cousins, nieces or nephews (Oxford Dictionary, 2018b:835). In this study, the relative will refer to any person that family members are caring for who has a mental illness.



#### **1.4.3.5 Caring**

'Caring', as described by the Oxford Dictionary (2018c:189), is the work or practice of looking after those unable to care for themselves, especially those who are aged or suffering from a certain illness. In this study, caring refers to the family members providing emotional and sometimes physical support to a relative with mental illness.

### **1.5 METHODOLOGICAL ASSUMPTIONS**

According to Polit and Beck (2017:12-13), the following methodological assumption is applicable to this research design: a naturalistic paradigm that believes that the researcher should interact with participants to obtain a holistic understanding of the phenomenon of interest by listening to the voices and interpretations of the participants. In this study, the researcher wanted to obtain a holistic understanding of the lived experiences of family members caring for a relative with mental illness. The Theory for Health Promotion in Nursing (University of Johannesburg, 2017:12) utilises the functional approach, meaning that nursing research should be undertaken in order to improve nursing practice. According to the researcher, this study will be useful in the nursing practice, and the community as a whole, as the lived experiences of family members caring for a relative with mental illness will be addressed and recommendations will be made.

A qualitative research design was utilised in this study. A qualitative research paradigm is referred to as research that elicits a participant's account of meaning, experience or perceptions. It also produces descriptive data in the participant's own written or spoken words. A qualitative research paradigm thus involves identifying the participant's beliefs and values that underlie the phenomenon (De Vos, Fouché, Strydom & Delport, 2011:65). The methodological assumptions reflect the researcher's view of the nature and structure of the science in the discipline. The assumptions are stated in terms of objectives and method of the research and the criteria for validity. Measures to ensure trustworthiness are discussed in detail in Chapter 2. The findings are supported by two principles of science which are logic and justification (Creswell & Poth, 2018:201). Logic, according to Gray, Grove and Sutherland (2017:164), is described as a science that involves valid ways of relating ideas to promote understanding. Logic is used in

order to determine the truth or to explain and predict a phenomenon. Justification, on the other hand, is defined as a way to demonstrate or prove to be just, right or valid (Gray et al., 2017:163-164).

## **1.6 RESEARCH DESIGN AND METHOD**

The research design and method employed in this study are described next.

### **1.6.1 Research design**

In this study, a qualitative, exploratory, descriptive and contextual research design was applied (Creswell, 2014:126) in order to capture the essence of the lived experiences of family members caring for a relative with mental illness. The terms 'exploratory', 'descriptive' and 'contextual' are discussed in more detail in the following chapter.

### **1.6.2 Research method**

The research was conducted in two phases. In Phase 1, the lived experience of family members caring for a relative with mental illness was explored and described. In Phase 2, specific recommendations to facilitate the mental health of family members caring for a relative with mental illness were described.

### **1.6.3 Phase 1: Exploration and description of the lived experiences of family members caring for a relative with mental illness**

The researcher followed a phenomenological approach in Phase 1. Descriptive phenomenology was utilised in this research (Gray et al., 2017:278) as the researcher described the lived experiences of family members caring for a relative with mental illness. The researcher bracketed her own preconceived opinions according to Husserl's descriptive phenomenological approach (Reiners, 2012:119). Reiners (2012:119) is of the opinion that the qualitative approach creates an opportunity for researchers to discover the phenomenon under study. According to Gray et al., (2017:278), the purpose of a phenomenological research approach is to describe

experiences as they are lived. The setting, population and sampling, data collection, data analysis and literature control were all considered as part of Phase 1.

- **Research setting**

The researcher worked at a public psychiatric hospital in Limpopo province. The researcher requested permission to undertake the study from the hospital manager and the Research Ethics Committee of the Faculty of Health Sciences at the University of Johannesburg. The unit managers of the wards identified family members caring for a relative with mental illness when they came to visit their relatives in specific wards. The unit managers contacted family members caring for a relative with mental illness to invite them to take part in the study. After the family members agreed to participate in the study, their contact information was provided to the researcher. The researcher contacted the family members in order to make arrangements to interview them. The setting for this study was the homes of family members caring for a relative with mental illness.

- **Population and sample**

The research population is the entire group of individuals who meet the criteria for inclusion in a study for which information is desired (Gray et al., 2017:329). The population of this study were the family members caring for a relative with mental illness. The researcher decided on a purposive sampling method (Gray et al., 2017:345), which involves the researcher's conscious selection of certain participants to be involved in the study. In this study, the purposive sampling of family members caring for a relative with mental illness was conducted.

Participants had to meet the following selection criteria in order to participate in the study:

- They could either be male or female
- They had to be living with the relative with mental illness
- They had to be 18 years or older

- Participants had to be able to communicate either in English, Xitsonga, Venda or Sotho. These languages are understood by the researcher.

- **Data collection**

Data collection and data analysis occur at the same time (Creswell, 2014:185). During data collection, the researcher utilised individual, phenomenological, in-depth interviews to explore and describe the phenomenon, as well as observation and field notes (Gray et al., 2017:256).

- **In-depth individual phenomenological interviews**

A qualitative research approach requires that the collected data must be rich in its description of the phenomenon under study. According to Gray et al., (2017:258), an interview is a method of data collection in which an interviewer obtains responses from a participant in a face-to-face encounter, through a telephone call, or by electronic means. Phenomenological interviewing is a specific type of in-depth interviewing grounded in the philosophical tradition of phenomenology, which is the study of lived experiences and the way one understands those experiences to develop a world view (Marshall & Rossman, 2011:148).

The researcher visited the participants at their homes and built rapport with the participants by being honest with them and showing them respect (Bevan, 2014:343). Participants should experience that the researcher is interested in them as individuals and that their uniqueness is respected and allow them to feel completely free. The researcher used in-depth interviews which are informal and less threatening for the participants. The researcher allowed participants to talk freely. The interview sessions lasted 40-60 minutes and were audio-recorded with permission from the participants. After the interviews, the audio-recordings were transcribed. In this study, the researcher asked one main question to participants: **“What is it like caring for a relative with mental illness?”**

- **Observation and field notes during interviews**

Gray et al., (2017:256) state that observation involves the researcher collecting data through listening, smelling, touching and seeing, with an emphasis on what is seen. Field notes are those notes written by the researcher by hand and compiled through observation during the qualitative interview process. During this study, the researcher made use of different types of field notes, including observational notes, personal notes, and methodological notes. She then converted them to write-ups so that they could be edited for accuracy and made readable for analysis (Bevan, 2014:344). These field notes are discussed in greater depth in Chapter 2.

- **Data analysis**

The purpose of data analysis is to make sense of all data that were collected by placing it in a format in order to be able to distinguish the content (Bevan, 2014:346). The researcher used Tesch's open coding (Creswell, 2014:197) to analyse and make sense of data that were collected. Units of meaning were identified from the data, transcribed interviews and field notes, and were linked together to form themes with supporting categories. The raw data were provided to an independent coder, purposively selected because of their experience in the qualitative research approach, using the same protocol for data analysis, separately from the researcher. The researcher and the independent coder met for a discussion on the results of the data analysis and reached consensus.

- **Literature control**

After the completion of data analysis, a literature review was done to support the essential meaning of the identified themes and sub-themes (Polit & Beck, 2017:354).

#### **1.6.4 Phase 2: Specific recommendations to facilitate the mental health of family members caring for a relatives with mental illness**

The specific recommendations to facilitate the mental health of families caring for a relative with mental illness were derived from the results of Phase 1.

### **1.7 MEASURES TO ENSURE TRUSTWORTHINESS**

Lincoln and Guba's (2013:104) description of trustworthiness was adhered to during the study and is described briefly in the sections that follow. Trustworthiness is confirmed when the findings provide rich descriptions of the lived experiences of family members caring for a relative with mental illness, as substantiated by participants (Gray et al., 2017:272). Measures to ensure trustworthiness include credibility, transferability, dependability and confirmability.

#### **1.7.1 Credibility**

Credibility relates to the notion of internal validity, which means that the participants recognise the meaning that they themselves give to a situation or condition, and the 'truth' of the findings in their own social context (Anney, 2014:279). According to Lincoln and Guba (2013:104), credibility corresponds to the internal validity criterion of positivism and refers to establishing confidence in the findings and interpretations of the research study. Houser (2012:425) is of the opinion that credibility is focused on the results accurately representing the underlying meaning of data; this is improved by prolonged engagement in the data collection process and triangulation. In this study, the researcher made use of long-term involvement with the participants, a reflective diary, peer evaluation, member checking, and in-depth interviews to ensure the credibility of the study. These are discussed in-depth in Chapter 2.

#### **1.7.2 Transferability**

Transferability refers to the degree to which the results of qualitative research can be transferred to other contexts with other participants. The findings in one context can be transferred to similar situations or participants. The researcher made a dense

description of the demographics of the participants. A rich description of the results with supporting direct quotations from the participants in the form of extracts from selected interviews is also presented (Anney, 2014:279). Lincoln and Guba (2013:104) state that transferability corresponds to the external validity criterion of positivism. In this study, transferability was enhanced by including men and women of varied ages, education and races caring for a relative with mental illness (Gray et al., 2017:272). Transferability is discussed in more depth in Chapter 2.

### **1.7.3 Dependability**

Lincoln and Guba (2013:105) use the term 'dependability' instead of reliability, which means that the findings of the study should be consistent and accurate to establish the trustworthiness of the study. This requires an audit, which follows the process and procedures used by the researcher in the study, and determines whether these findings are acceptable, that is, dependable (Gray et al., 2017:274). Dependability therefore refers to the provision of evidence; if it were to be repeated with the same or similar participants in the same or similar context, its findings would be similar. A dense description of the research methodology was given. These are discussed in-depth in Chapter 2.

### **1.7.4 Confirmability**

Lincoln and Guba (2013:105) refer to 'confirmability' as the meaning that an audit or decision trail where readers can trace data to their sources. Gray et al., (2017:272) state that the findings, conclusions and recommendations should be supported by the data and there should be an internal agreement between the investigator's interpretation and the actual evidence. This is accomplished by incorporating an audit procedure. The audit is done of the whole research process to ensure confirmability. Trustworthiness is discussed in greater depth in Chapter 2.

## **1.8 ETHICAL CONSIDERATIONS**

In this study, human participants were involved, and as such, their rights were protected, so ethical principles were identified and adhered to. Dhai and McQuoid-

Mason (2011:11-14) indicate that there are four principles to be considered when doing research, namely autonomy, beneficence, non-maleficence and justice. In this study, these principles were all adhered to throughout the project (see Appendix A). Each principle is binding unless it clashes with equal or stronger obligations.

### **1.8.1 Principle of autonomy**

This principle involves respecting people's rights to make decisions based on their personal values and beliefs, free from the controlling influence of others. It also takes into consideration the individual's self-determination and is the bases of informed consent (See Annexure B). According to Dhai and McQuoid-Mason (2011:12), the researcher has the responsibility to ensure that participants are not unduly influenced to participate. They receive all the relevant information regarding the study, i.e. the purpose of the study, the risk-benefit ratio, right to privacy, confidentiality and anonymity to ensure them that they would not be exposed to any kind of harm.

It is an individual's right to determine the time, extent and general circumstances under which personal information is shared with or withheld from others (Gray et al., 2017:161). The participants determined the time and place where the interviews were held with the researcher. The participants were informed that the researcher would provide each participant with a number or code, or that they could devise their own codes to ensure that their identities are not recognised and kept anonymous. The list of real names was destroyed after data analysis was completed, and the researcher only kept the matching code numbers in a safe place. All participants had time to ask questions relating to the study. They were informed about their right to withdraw from the study at any time if they wished, and will be informed of the findings of the study. Participants were informed that the audio-recordings of the interviews would be destroyed two years after the publication of the research.

### **1.8.2 Principle of non-maleficence**

The principle of non-maleficence states that one should do no harm to others. The researcher ensured that during this study, the participants were protected against any kind of harm and there was no potential risk to their psychological well-being, mental



health, personal values or dignity. The participants were not exposed to risks greater than or additional to those to which they are exposed to in their daily life. According to Gray et al., (2017:161), when the risk is high the researcher must make every effort to reduce it and to maximise the benefit.

### **1.8.3 Principle of beneficence**

To adhere to the principle of beneficence, the researcher needs to secure the wellbeing of the participants' right to protection from discomfort and harm. It can either be physical, psychological, emotional, spiritual, economic, social or legal (Gray et al., 2017:161). In this study, the researcher always used good clinical judgement to manage each interview with the participants (Brink, Van der Walt & Van Rensburg, 2012:36). The researcher avoided harming participants by carefully structuring the questions and monitoring the participants for any signs of distress.

### **1.8.4 Principle of justice**

The researcher treated participants with fairness at all times during the process of this study by making sure that all participants were respected and treated equally (Gray et al., 2017:161). Participants were selected for reasons that directly related to the research problem and not because they were readily available or could be easily manipulated (Dhai & McQuoid-Mason, 2011:12).

## **1.9 DIVISION OF CHAPTERS**

This research study is divided into four chapters. Chapter 1 comprises of the introduction and overview of the research study, Chapter 2 presents the research design and research methods, which continue to Chapter 3, where the lived experiences of family members caring for a relative with mental illness are presented by means of the research findings. In Chapter 4, the specific recommendations to facilitate the mental health of family members caring for a relative with mental illness are presented and discussed.

## 1.10 CONCLUSION

In this chapter, the researcher broadly discussed the overview of the study, focusing on the background and rationale of the research question and objectives. In addition, the research design and method were briefly outlined and ethical considerations were mentioned. These included the principles of autonomy, beneficence, non-maleficence and justice. Measures to ensure trustworthiness were provided. In Chapter 2, the researcher focuses primarily on the research design and research method that was used in this study.



## **CHAPTER 2**

### **RESEARCH DESIGN AND METHOD**

#### **2.1 INTRODUCTION**

In the previous chapter, the researcher outlined the background and overview of the research study. In Chapter 2, the researcher discusses the research design and the research method of the study in detail. The researcher describes the population and sampling methods of the study by focusing on the sampling criteria and the requirements of the participants. The researcher also explores the trustworthiness strategies, which include credibility, dependability, transferability as well as confirmability. Finally, the researcher presents the ethical considerations that were adhered to in this study, which consisted of autonomy, beneficence, non-maleficence and justice.

#### **2.2 RESEARCH PURPOSE AND OBJECTIVES**

The purpose of this study was to understand the lived experiences of family members caring for a relative with mental illness and to describe specific recommendations to facilitate the mental health of the family members caring for a relative with mental illness in Giyani, Limpopo province.

The research objectives were:

- to explore and describe the lived experiences of family members caring for a relative with mental illness in Giyani, Limpopo province; and
- to describe specific recommendations to facilitate the mental health of family members caring for a relative with mental illness.

#### **2.3 RESEARCH DESIGN AND METHOD**

The research design and method are described in the sections that follow.

### **2.3.1 Research design**

In this study, a qualitative exploratory, descriptive, contextual design was applied (Creswell, 2014:126) in order to capture the essence of the lived experiences of family members caring for a relative with mental illness. The terms 'qualitative', 'exploratory', 'descriptive' and 'contextual' are discussed in more detail next.

#### **2.3.1.1 Qualitative research**

Creswell and Poth (2018:4) state that qualitative research is an approach used for exploring and understanding the meaning which individuals or groups of people ascribe to a social or human problem. According to Brink et al., (2012:120), qualitative research is used by researchers who wish to explore the meaning, or describe and provide an in-depth understanding of, human experiences such as pain, grief, hope or caring, or other unfamiliar phenomena. The aim of qualitative research, according to Brink et al., (2012:2), is to study people in their natural setting and to collect data naturally as it occurs. It is a method of naturalistic inquiry which is usually less obstructive and does not manipulate the research setting. Therefore, qualitative research is referred to as social research that is conducted in the field or natural setting, and analysed largely in a non-statistical manner. Brink et al., (2012:121) further explain that a qualitative research approach is a broad range of research designs and methods used to study phenomena of social action. In this study, the researcher explored the lived experiences of family members caring for a relative with mental illness in a psychiatric hospital in Giyani, Limpopo province.

#### **2.3.1.2 Exploratory research design**

Rubin and Babbie (2013:41) state that an exploratory research design arises when there is a scarcity of basic information on a new area of interest. In using this research design, the researcher aims to yield new insights or provide an in-depth understanding of the perspectives and experiences of the research participants (Babbie & Mouton, 2010:93). An exploratory research design enquires into the circumstances in a community, how people get along in their setting, what meaning they give to their actions and what concerns them (Engel & Schutt, 2010:9). In an exploratory research

design, according to Babbie and Mouton (2010:79), a large amount of unstructured data is normally collected in order to explore a new topic, or to be responsive to new concerns by breaking new ground through exploring a developing problem area to work on topics about which very little information is available and to gain a broader understanding of a situation, community or person. This is supported by Rubin and Babbie (2013:90-91) and Pierson and Thomas (2010:440), who concur that an exploratory purpose does not only apply to new concerns, but is also appropriate for more persistent phenomena, for testing the feasibility of undertaking a more extensive study, for developing the methods to be employed in the study, and for generating more focused research questions and hypothesis for additional investigations (Rubin & Babbie, 2013:90; Babbie & Mouton, 2010:79). In this study, the researcher utilised an exploratory research design to gain an in-depth understanding of the lived experiences of family members caring for a relative with mental illness.

### **2.3.1.3 Descriptive research design**

Descriptive research is defined by Gray et al., (2011:256) and Mjacu (2015:11) as a design that gathers information about the characteristics of a phenomenon and describes the aspects of a situation or experiences as they occur. The purpose of a descriptive research design is to observe, describe, and document aspects of a situation as it naturally occurs, and sometimes to serve as a starting point for hypothesis generation or theory development (Polit & Beck, 2017:226). Brink et al., (2012:3) state that descriptive research provides an in-depth description of family members. This is supported by Onwuegbuzie and Byers (2014:18), who claim that descriptive research follows on the exploratory research design and attempts to describe a situation, environment, process or relationships. Onwuegbuzie and Byers (2014:18) indicate that a descriptive research design describes the data that are obtained through exploratory research and enhances the insight regarding the phenomena of interest. In this study, the focus was on the meaning family members caring for a relative with mental illness in Giyani, Limpopo province gave their experiences.

#### **2.3.1.4 Contextual research design**

According to Ngako, Van Rensburg and Mataboge (2012:3), a contextual research design is concerned with making sense of human experience from within the context and perspectives of their experiences. In a contextual research design, the researcher conducts field interviews with participants in their homes, exploring a new area of study or complex issues that embrace the perspectives of the study population and the context in which they live (Holloway & Wheeler, 2010:07). Holloway and Wheeler (2010:05) state that the context in a research study includes the environment and conditions under which the study takes place. The context of this study was family members caring for a relative with mental illness who were admitted to a psychiatric hospital in Giyani, Limpopo province.

### **2.4 RESEARCH METHOD**

The researcher conducted this study in two phases. In Phase 1, the lived experiences of family members caring for a relative with mental illness were explored and described. In Phase 2, specific recommendations to facilitate the mental health of family members caring for a relative with mental illness were described.

#### **2.4.1 Phase 1: Exploration and description of the lived experiences of family members caring for a relative with mental illness**

Brink et al., (2012:121) state that phenomenological research examines human experience through the descriptions that are provided by the people involved. Edmonds and Kennedy (2013:136) add that a phenomenological approach is the description of an individual's immediate experience. According to Creswell and Poth (2018:14), phenomenological research is defined as the design of inquiry coming from philosophy and psychology. A phenomenological approach places the emphasis on understanding several individuals' shared experiences of a phenomenon, with the importance placed on understanding these experiences. This approach supports the development of a deeper understanding of the phenomenon. The researcher bracketed her own preconceived opinions according to Husserl's descriptive phenomenological design (Reiners, 2012:119). Bracketing, according to Creswell and

Poth (2018:126), is a way of increasing the scientific rigour in the phenomenological approach and this technique is used in order for researchers to avoid being judgemental towards study participants. Parahoo (2014:216) stresses the importance of researchers ensuring that they try to see things through the eyes of the people they are interviewing. In this study, the aim was to capture the lived experiences of family members caring for a relative with mental illness. Family members' lived experiences were the central phenomenon which was explored in this qualitative study.

#### **2.4.1.1 Research setting**

The research setting, as defined by Gray et al., (2017:40), is the physical location and conditions under which data collection takes place in a study. The researcher worked at a public psychiatric hospital in Giyani, Limpopo province, and requested permission to conduct the study from the hospital manager (Annexure A) and the Research Ethics Committee of a Faculty of Health Sciences at the University of Johannesburg (Annexure A). The unit managers of the wards identified family members caring for a relative with mental illness when they came to visit their relatives in specific wards. The unit managers contacted the family members to invite them to take part in the study. After the family members agreed to participate in the study, their contact information was provided to the researcher. The researcher then contacted the family members to make arrangements to interview them. The setting for this study was the family members' homes.

#### **2.4.1.2 Population and sampling**

The population is the entire group of individuals who meet the criteria for inclusion in a research study for which information is desired (Gray et al., 2017:329-330). A population is defined by Parahoo (2014:259) as the total number of units from which data is collected. These units may be individuals, organisations, events or articles.

The accessible population is described by Gray et al., (2017:330) as the portion of the target population to which researchers have reasonable access. The population in this study was the family members caring for a relative with mental illness. This population was accessible to the researcher as she worked in the psychiatric hospital where the

relatives with mental illness were admitted time and again, and their family members came to visit them. In this study, the criteria for sampling included all family members caring for a relative with mental illness who were admitted to the psychiatric hospital where the study was conducted. Participants had to meet the following selection criteria for inclusion in the study:

- Participants could either be male or female
- Participants had to be living with the relative with mental illness
- Participants had to be 18 years or older
- Participants had to be able to communicate either in English, Xitsonga, Venda, or Sotho. These languages were understood by the researcher.

#### **2.4.1.3 Role of the researcher**

Creswell and Poth (2018:45) state that researchers are the key research instruments as they are responsible for collecting data themselves through examining documents, observing behaviour and interviewing participants. According to Marshall and Rossman (2011:386), the researcher is responsible for presenting data that are clear and sufficiently detailed to allow other people to understand how the research was conducted. Researchers are also responsible for ensuring that readers are informed of the plausible explanation for their findings; for example, if there is any information or sections in their research that they wish to include (Parahoo, 2014:386).

#### **2.4.1.4 Data collection**

Gray et al., (2017:256) state that data collection and data analysis in qualitative research occur simultaneously and the process is complex, whereby the researcher is involved in 'perceiving', 'reacting', 'interacting', 'reflecting' and 'recording' data at the same time. Methods of data collection in phenomenological descriptive studies are mainly interviews and written descriptions (Parahoo, 2014:218). In this study, the researcher used different methods of data collection. In-depth, individual, phenomenological interviews were conducted where the researcher explored and described the phenomenon and used bracketing to avoid bias in the research. Interviews, according to Parahoo (2014:218), should be long enough to obtain concrete



descriptions and should be recorded with permission from participants to allow a detailed analysis of the transcripts. Field notes were written based on observations clarified during the interviews and the researcher kept records of her observations.

- **In-depth individual phenomenological interviews**

A qualitative research approach requires the collected data to be rich in description of the phenomenon under study. The researcher visited the participants at their homes. According to Gray et al., (2017:259), an interview is a method of data collection in which an interviewer obtains responses from participants in a face-to-face encounter. In this study, in-depth phenomenological interviews were employed in order to produce dense and quality information. The researcher used in-depth interviews which were informal and less threatening for the participants. She allowed them to talk freely. The interview sessions lasted 40-60 minutes and were audio-recorded with permission from the participants. These recordings were then transcribed. In this study, the researcher asked one main question to participants: **“What is it like caring for a relative with mental illness?”** Follow-up questions, probing, and minimal verbal responses were used to confirm or to look for the underlying meaning of the statements given by the participants (De Vos et al., 2011:347).

- **Observation and field notes during interviews**

Brink et al., (2012:150) define ‘observation’ as a technique for collecting descriptive data on behaviour, events and situations. The observation was considered to be useful as it allowed the researcher to observe the behaviours as they occurred. Observation can either be structured or unstructured (Parahoo, 2014:336; Brink et al., 2012:150).

Field notes are handwritten notes by the researcher, compiled through observation during the qualitative interview process. During this study, the researcher made use of different types of field notes such as observational notes, personal notes, methodological notes and theoretical notes (Polit & Beck, 2017:230). The researcher later processed these notes and converted them into write-ups so that they could be edited for accuracy and made readable for analysis (Bevan, 2014:344).

#### **2.4.1.5 Data analysis**

The researcher sought meaning from all available raw data in order to analyse the qualitative data. The purpose of data analysis is to make sense of all the data that were collected by placing it in a specific format in order to be able to distinguish the content (Bevan, 2014:345). Data analysis is described as the process of making sense of collected data. It involves the process of preparing the data for analysis and conducting different analyses. As stated by Creswell and Poth (2018:195), data analysis in qualitative research takes place hand-in-hand with other parts of the study, which include data collection and the recording of findings. During data analysis, the researcher went through the collected data and highlighted significant statements, sentences or quotes that provided an understanding of the lived experiences of family members caring for a relative with mental illness. In this study, Tesch's open coding method was applied, which comprise eight steps of data analysis (Creswell & Poth, 2018:198). Direct quotes were also extracted from the transcriptions of the in-depth phenomenological audio-recorded interviews and field notes.

Tesch's open coding eight steps that were used during data analysis included:

##### **STEP 1:**

The researcher read all the transcriptions and collected field notes in order to get a sense of the data or ideas. She then jotted down important facts as they came to mind.

##### **STEP 2:**

The researcher identified and read collected data and tried to figure out what it was all about; meaning, she analysed collected data by trying to think about the underlying meaning of the content.

##### **STEP 3:**

After going through all the collected data, the researcher clustered topics that were similar together and separated those that were unique. In this study, the researcher read all the transcripts from the interviews and highlighted sentences in the data, which she labelled in the margin according to the themes displayed in the highlighted

narratives. Each category was clustered into themes and named according to the themes represented by the quotes.

**STEP 4:**

In this step, data were coded. The researcher marked topics as abbreviated earlier, placed these into coding, and data were compared in order to ensure that no themes were left out.

**STEP 5:**

The researcher then grouped together data that were related to reduce the number of categories. The researcher used a table to convey a summary of the identified themes and categories.

**STEP 6:**

In this stage, the researcher made the final decision and ensured that all categories were correctly abbreviated and placed in alphabetical order.

**STEPS 7 & 8:**

Data were interpreted at this stage when the researcher interpreted the meaning of the collected data. This was done after the researcher had assembled data from each category.

The researcher repeated this process with all the interviews until data saturation was reached. After an analysis of all the collected data, which consisted of recorded interviews, field notes and observations, these were given to an independent coder. The independent coder was purposively selected because of their experience in the qualitative research approach using the same protocol for data analysis, separately from the researcher. The researcher and the independent coder then met for a consensus discussion on the results of the data analysis.

#### **2.4.1.6 Literature control**

The researcher in this study used existing published and research books on studies related to the research question. The results were described in the context of the

findings in the available body of knowledge. Literature from the literature control was then compared with the findings of the present study to determine current knowledge on the phenomenon (Brink et al., 2012:72).

#### **2.4.2 Phase 2: Specific recommendations to facilitate the mental health of familymembers caring for a relative with mental illness**

These specific recommendations were generated based on the results that were derived from Phase 1 and included a description of how the mental health of family members caring for a relative with mental illness can be facilitated.

### **2.5 MEASURES TO ENSURE TRUSTWORTHINESS**

According to Lincoln and Guba (2013:103), trustworthiness is described as the quality of an inquiry to determine whether the findings and interpretations were an outcome of a systematic process, and whether the findings and interpretations can be trusted. Guba’s model of trustworthiness (Lincoln & Guba, 2013:84) were adhered to during the study and is described briefly in Table 2.1.

**TABLE 2.1: MEASURES TO ENSURE TRUSTWORTHINESS**

<b>STRATEGY</b>	<b>CRITERIA</b>	<b>APPLICABILITY</b>
Credibility	Prolonged engagement	The researcher established rapport by spending enough time with the participants. Trust was built by honouring anonymity, honesty and openness.
	Triangulation	Data were collected using multiple methods of data collection, namely in-depth phenomenological interviews, observation and field notes.  Literature control was conducted as a method of triangulating data.

STRATEGY	CRITERIA	APPLICABILITY
	Member checking	Member checking was done informally during interviews, where participants were involved in clarifying and summarising. Discussions provided the participants with an opportunity to add material, make changes and present alternative interpretations.
	Reflective journals	The researcher used reflective journals and field notes during the interviews.
	Structural coherence	The study focused on family members caring for a relative with mental illness. The lived experiences of family members caring for a relative with mental illness were described.
	Interviews	The researcher used reframing of questions, repetition and expansion of questions to ensure credibility during interviews.
Transferability	Purposive sampling	The researcher purposively selected participants.
	Dense description of the demographics	The demographics of the participants were discussed densely.
	Rich description of results	In-depth descriptions of the results with verbatim quotations from the interviews were provided. The results were contextualised in the literature.

STRATEGY	CRITERIA	APPLICABILITY
Dependability	Stepwise replication of the research method	A stepwise replication of the research method was applied.
	Dense description of research methodology	The researcher described all aspects of the study, which included the research method, characteristics of the sample and process and data analysis.
	Code recording of data	The researcher discussed results with an independent coder after data analysis to reach a consensus.
Confirmability	Audit trail	The researcher kept the documents of the audio-recorded interviews, transcribed materials and field notes as audit material.
	Chain of evidence	The researcher kept all the transcripts and field notes as proof of the work done.

### 2.5.1 Credibility

Parahoo (2014:406) defines 'credibility' as the extent to which the findings of the study reflect the experience and perceptions of those who provided the data. The findings must also be credible to those who subsequently read the report. Brink et al., (2012:172) describe credibility as the criterion that alludes to confidence in the truth of the data and the interpretation thereof. Lincoln and Guba (2013:104) add that credibility corresponds to the internal validity criterion of positivism, and refers to establishing confidence in the findings and interpretations of a study. Techniques used for ensuring credibility – and applied in this study – included prolonged engagement, triangulation of sources, reflective journal, structural coherence, members checking and interviews.

#### 2.5.1.1 Prolonged engagement in the field

Prolonged engagement in the field refers to the researcher spending time with the participants until data saturation has been reached. The researcher explained the

reason for conducting the research to the participants and all the processes that would be followed during the study. These steps ensured that rapport was established between the researcher and the family members (Marshall & Rossman, 2011:40). It also allowed the researcher to gain an in-depth understanding of the phenomenon. Brink et al., (2012:172) state that the researcher spending a lot of time with the family members allows her to gain specific understanding of aspects about the family members, including their perceptions, views, their culture and experiences.

### **2.5.1.2 Triangulation**

This trustworthiness technique involves the researcher collecting data regarding the topic from multiple sources of the same type in order to determine if different sources provide different information (Lincoln & Guba, 2013:106). Triangulation, according to Holloway and Wheeler (2010:115), enhances the trustworthiness and authenticity of studies. Polit and Beck (2017:745) define 'triangulation' as the use of various data collection methods to address a research problem, such as observation and in-depth interviews. The purpose of triangulating the research data is to ensure the accuracy of the collected data.

### **2.5.1.3 Member checking**

After the researcher collected data and completed data analysis, she went back to the family members and showed them the findings in order for them to correct misinterpreted data and clarify missing information. Marshall and Rossman (2011:221) indicate that in member checking the researcher devises a way to ask the participants whether she got it right or not. The researcher primarily gave a summary of the research findings to the participants before writing up her study and asked for reactions, corrections and further insights.

### **2.5.1.4 Reflective journal**

This technique, according to Lincoln and Guba (2013:109), refers to the way in which the researcher keeps a journal in which she carries out conversations with herself on topics related and not related to the study, as in a diary. The purpose of a reflexive

journal is to keep a record of the changes occurring in the research. During data collection, the researcher kept a reflective journal in which she jotted down all her observations and experiences during the interviews, including aspects such as metaphors, non-verbal cues, and expressions (Lincoln & Guba, 2013:109). Anney (2014:279) states that a reflexive journal is an assessment of the influence of the researcher's own background, perceptions and interests in the qualitative research process that includes the researcher's personal history.

#### **2.5.1.5 Structural coherence**

According to Lincoln and Guba (2013:106), credibility in research is supported by establishing structural coherence, ensuring no unexplained inconsistencies between data and the participants' interpretations. In this study, data focused on the lived experiences of family members caring for a relative with mental illness. A variety of phenomena are sought after in qualitative research to ensure credibility when correctly describing and understanding data.

#### **2.5.1.6 Interviews**

Credibility can also be enhanced within the interviewing process. The reframing of questions, repetition of questions, or expansion of questions on different occasions are ways in which to increase credibility (Lincoln & Guba, 2013:105). Credibility was also supported when interviews or observations were internally consistent; when there was a logical rationale about the same topic in the same interview or observation. In addition, indirect questions about the participants' experiences (questions such as "Do you know others who have this experience?") and structured hypothetical situations are methods that can be used to verify observations and meanings in a study.

#### **2.5.2 Transferability**

Lincoln and Guba (2013:106) use the term 'transferability' instead of generalisation, which means that the findings in one context can be transferred to similar situations or participants. Demonstrating transferability of findings is the responsibility of those who wish to apply it in another context. The researcher chose purposive sampling as a



strategy to enhance transferability in this study. The researcher made a dense description of the demographics of the participants. A rich description of the results with supporting direct quotations from the participants in the form of extracts from selected interviews were also presented. Polit and Beck (2017:585) confirm that transferability refers to the potential for extrapolation, meaning the extent to which findings can be transferred to, or have applicability in, other settings or with different participants. In this study, the researcher was not interested in generalising the findings but rather defining observations within the specific context in which they occur.

### **2.5.2.1 Purposive sampling**

Parahoo (2014:382) states that purposive sampling is when the researcher carefully selects participants on the basis of the varied experiences they may bring to the study. A purposive sampling method, according to Gray et al., (2017:345), involves the researcher's conscious selection of certain participants to be involved in the study. In this study, the purposive sampling of family members caring for a relative with mental illness was undertaken.

### **2.5.2.2 Dense description of demographics**

The researcher provided dense background information about the participants and the research context and setting to allow others to assess how transferable the findings are. The adequacy of the database is especially important in describing participants with mental illness, because persons with similar conditions may be entirely different in terms of, for example, functional ability or severity of symptoms (Lincoln & Guba, 2013:105).

### **2.5.2.3 Rich description of results**

The researcher collected rich descriptive data which allowed comparison of the context to other possible contexts to which transfer might be contemplated. A rich description of the context was provided in order to make a judgement about the study fitting in with other possible contexts (Lincoln & Guba, 2013:105). The researcher gave a rich description of results with supporting direct quotations from participants.

### **2.5.3 Dependability**

Dependability, as described by Gerrish and Lacey (2010:139), refers to the transparency of the research process and decision-line. In this study, reliable research methods were used and described in detail to ensure that the results were trustworthy. According to Anney (2014:279), as well as Lincoln and Guba (2013:105), dependability is used instead of reliability, which means that the findings of the study should be consistent and accurate to establish the trustworthiness of the study. This required an audit, which followed the process and procedures used by the researcher in the study, and determined whether these findings were acceptable, that is, dependable. After data analysis was completed by the researcher, an independent coder was involved in independently analysing the collected data to ensure that the results obtained from the data analysis were dependable. The researcher and independent coder then met and discussed results to ensure consensus in the identification of themes.

The techniques used to ensure the dependability of the study included stepwise replication of the research method, dense description of research methodology, and the code-recoding of data (Polit & Beck, 2017:585).

#### **2.5.3.1 Stepwise replication of research method**

Anney (2014:278) describes stepwise replication as a qualitative data evaluation procedure where two or more researchers analyse the same data separately and compare the results. If there are any inconsistencies that arise from these separate analyses, they are addressed to improve the dependability of the study, and if the results of the analyses are similar, it serves as evidence of the dependability of the study findings. The steps taken in this study are discussed later in the chapter.

#### **2.5.3.2 Dense description of research methodology**

Dependability can also be enhanced through triangulation to ensure that the weaknesses of one method of data collection are compensated by the use of alternative data-gathering methods (Lincoln & Guba, 2013:105). Asking colleagues and methodological experts (peer examination) to check the research plan and

implementation is another means of ensuring dependability. In this study, the researcher enhanced stability by repeated observation of the same event and requisitioning participants about major issues to ensure credibility.

### **2.5.3.3 Code-recoding of data**

With the code-recoding of data, the researcher recoded the same data again two weeks after the initial coding process. Coding, according to Creswell and Poth (2018:197-198), refers to coding of data as a process of organising the data by bracketing portions and writing words representing a category in the margins. The recodings are then compared to see if they are the same or if there are any difference. In this study, the recoded data will remain under lock and key for at least two years after the publication of the study, and will then be destroyed

### **2.5.4 Confirmability**

According to Anney (2014:279), confirmability refers to the extent to which the findings of an investigation can be confirmed or verified by others. In this study, the researcher presented rich direct quotes from the participants that depicted each emerging theme. The interviews were digitally recorded and transcribed verbatim to avoid the possibility of bias (Cope, 2014:89). Confirmability was concerned with establishing that data and interpretations of the findings were not figments of the inquirer's imagination but clearly derived from the data. Confirmability was also established using a reflexive journal or practice, which is described by Anney (2014:279) as a reflexive document kept by the researcher in order to reflect on cautiously interpreted, and planned data collection.

Holloway and Wheeler (2010:303) describe confirmability as objectivity in research; it should be possible to trace the source of the research data. In this study, the researcher made sure that she remained faithful to academic and ethical requirements. The outcome of this study was the original work of the researcher, and to ensure confirmability, the researcher kept all the field notes, observations and memos obtained during data collection.

#### **2.5.4.1 Audit trail**

After the independent coder analysed the collected data, the data still needed to be submitted to the research supervisor and co-supervisors for evaluation. Thereafter, the study was submitted for further assessments of trustworthiness. All the field notes written during data collection, the data analysis process and the transcripts of the recordings, as well as the recordings themselves, were available when the supervisor and co-supervisors evaluated the analysed data and findings. This served as tools for the supervisors to audit how the researcher arrived at the results of the findings (Lincoln & Guba, 2013:109).

#### **2.5.4.2 Chain of evidence**

The researcher triangulated multiple methods, data sources and theoretical perspectives to test the strengths of the ideas (Lincoln & Guba, 2013:106). In this study, the researcher provided all the recorded interviews, field notes and transcripts used as evidence of the work done.

### **2.6 ETHICAL CONSIDERATIONS**

Ethical issues are considered in all research studies. A study is conducted by applying principles that protect participants from harm and risk (Holloway & Wheeler, 2010: 53). Creswell and Poth (2018:92) state that ethical issues in research command increased attention. Ethical considerations that need to be anticipated are extensive and should be reflected in the research process. Human participants were involved in this study; as such, their rights had to be protected (Dhai & McQuoid-Mason, 2011:14-15). The researcher applied four ethical principles, namely the principle of autonomy, the principle of beneficence, the principle of non-maleficence, and the principle of justice which were discussed in detail in Chapter 1.

### **2.7 SUMMARY**

In Chapter 2, the researcher discussed the research design and research method in detail. The discussion of the research design included qualitative research, exploratory

research designs and contextual research designs. The description of the research method included two phases; in Phase 1, the lived experiences of family members caring for a relative with mental illness was explored and described. The research setting, population and sampling, selection criteria, data collection, and data analysis were the focus of this chapter. Measures to ensure trustworthiness, which covered credibility, confirmability, dependability and transferability were also dealt with in this chapter. Moreover, the ethical considerations discussed in this chapter were the principle of autonomy, the principle of beneficence, the principle of non-maleficence and the principle of justice. Phase 2 was also described.

In Chapter 3, the researcher provides the description of the demographic profile of the sample and presents a detailed discussion of the findings of the study, together with the literature control.



## CHAPTER 3

### LIVED EXPERIENCES OF FAMILY MEMBERS CARING FOR A RELATIVE WITH MENTAL ILLNESS

#### 3.1 INTRODUCTION

In Chapter 2, the researcher focused on the description of the research design and the research method. In Chapter 3, the lived experiences of family members caring for a relative with mental illness admitted in a psychiatric hospital in Giyani Limpopo Province is presented by means of the research findings. The central storyline is expressed as depicted by the themes and categories.

#### 3.2 DESCRIPTION OF THE DEMOGRAPHIC PROFILE OF THE SAMPLE

A total of eight family members caring for a relative with mental illness volunteered to participate in the study. Participants consisted of one male and seven females. The participants were between the ages of 43 to 68. The family members who met the inclusion criteria of caring for a relative with mental illness on a daily basis and who were eighteen years and older were invited to participate. Five participants were married, two were single, and one was widowed.

**TABLE 3.1: DESCRIPTION OF THE DEMOGRAPHIC PROFILE OF THE PARTICIPANTS**

Participant	Gender	Age	Years in caring	Marital status	Relationship to the relative with mental illness
Participant 1	Male	60	52	Married	Brother
Participant 2	Female	53	35	Single	Mother
Participant 3	Female	67	48	Married	Sister-in-law
Participant 4	Female	50	30	Single	Mother
Participant 5	Female	68	18	Widow	Mother
Participant 6	Female	49	21	Married	Mother

Participant	Gender	Age	Years in caring	Marital status	Relationship to the relative with mental illness
Participant 7	Female	43	24	Married	Mother
Participant 8	Female	67	47	Married	Sister-in-law

### 3.3 RESEARCHER'S EXPERIENCE OF CONDUCTING THE INTERVIEWS

The researcher's personal experience while collecting data was that sometimes she felt emotionally touched by what the participants were explaining and the way in which they related their stories. Some of the participants explained that they loved their relatives with mental illness, but it appeared that the relatives with mental illness tended to hate their carers. In one interview, the researcher felt sad since the participant was the same age as the researcher and she was caring for both her husband and son who were living with mental illness. The son was also the same age as the researcher's son. It was clear to the researcher that these family members caring for a relative with mental illness wanted someone to hear their stories about their lived experiences of caring for a relative with mental illness.

### 3.4 DISCUSSION OF THE RESULTS AND LITERATURE CONTROL

The discussion of the results of the lived experiences of family members caring for a relative with mental illness in a psychiatric hospital in Giyani, Limpopo province is presented in a central storyline and essay format based on the outline provided in Table 3.2. Themes and categories presented in this study were reached through the process of content analysis using Tesch's (Creswell & Poth, 2018:198) open coding of data analysis (See Section 2.4.1.5). Data saturation was reached during the fifth interview when the same themes emerged repeatedly. Three more interviews were conducted to enhance the findings. The discussion in this chapter was guided by the central storyline, representing the principle of family members' experiences of the research phenomenon, followed by the discussion of the themes and categories.

### 3.4.1 Central storyline

Family members caring for a relative with mental illness experienced being alert about the safety of their relative with mental illness. They experienced that their relative was not mentally stable as evidenced by erratic behaviour. They experienced various challenges in caring for their relative with mental illness. The family members also experienced coping strategies in caring for their relative with mental illness.

### 3.4.2 Themes and categories from findings

Table 3.2 lists the themes and categories as obtained from the collected data from family members caring for a relative with mental illness.

**TABLE 3.2:THEMES AND CATEGORIES OF THE LIVED EXPERIENCES OF FAMILY MEMBERS CARING FOR A RELATIVE WITH MENTAL ILLNESS IN GIYANI, LIMPOPO PROVINCE**

THEMES	CATEGORIES
<b>Theme 1:</b> Family members experienced being alert about the safety of their relative with mental illness	3.4.2.1 Family members experienced frequent risk assessments of their immediate surroundings 3.4.2.2 Family members experienced the need to provide better security
<b>Theme 2:</b> Family members experienced that their relative was not mentally stable as evidenced by erratic behaviour	3.4.3.1 Family members experienced that their relative with mental illness had childlike behaviour 3.4.3.2 Family members experienced that their relative with mental illness had uncontrollable behaviour
<b>Theme 3:</b> Family members experienced challenges caring for a relative with mental illness	3.4.4.1 Family members experienced financial challenges 3.4.4.2 Family members experienced caring challenges which resulted in feeling obliged to care and exhaustion 3.4.4.3. Family members experienced rumours which were spread by community members



THEMES	CATEGORIES
<b>Theme 4:</b> Family members experienced coping strategies in caring for a relative with mental illness	3.4.5.1. Family members experienced support from extended family members 3.4.5.2. Family members experienced coming to a realisation about the mental illness, accepting the reality that it was a lifetime situation

### 3.4.2.1 Theme 1: Family members experienced being alert about the safety of their relative with mental illness

Family members caring for a relative with mental illness were of the opinion that they were at risk of being injured or killed by their violent and aggressive relative with mental illness, and as such, families lived in fear. Some family members reported that they were attacked by their relatives with mental illness. Destruction to property was also reported by many families, as well as being at risk of injuries (Monyaloue, et al. 2014:11). This theme had two categories which are discussed next.

- **Family members experienced frequent risk assessments of their immediate surroundings**

During the interviews, family members caring for a relative with a mental illness described that their relative with mental illness was not safe from the community. Community members believed that they were not mentally ill but simply being destructive due to the abuse of drugs. As a result, community members ended up hurting them. One of the family members reported that they were also being beaten by their relative with mental illness.

In one scenario, the family member reported that they kept their relative with mental illness busy during the day by giving them chores to do in order to keep them in one place without experiencing boredom, and to distract them from thinking of going out, which was unsafe for them. The participant related his story as follows:

*“Sesi M u hlayisekile swinene, na laha kaya gede hi tshama hi khiyile. Na pfumela ku na nwina mi kume yi khiyiwile.”* (“Sister M is very much safe, here at home the gate is always locked. I believe you also found it locked.”) (P1, 60 years, brother)

Other participants reported being of the opinion that the safety of their relatives with mental illness was at risk as some people hated them or talked bad about them. They were scared that people might poison their relatives with mental illness. Participants shared:

*“Ho pfa hi va na ku chava a ni vanhu va cheleriwa kwala tikweni.”* (“Sometimes we are scared about his safety since they poison people in our community.”) (Participant 3, 67 years, sister-in-law)

*“Se ma swi vona kuna swo dlaya va nga va nyika ivi va hi lovela”* (“They can feed him with poison he can die at any time.”) (Participant 3, 67 years, sister-in-law)

*“Vuhlayiseki nile ka mina na byi lava, na chava ku ri ni vani nga hlayisekangi loko a ri kona swi ni tikela swinene”* (“I personally want a good security around me, I feel very much unsafe when he is around me.”) (Participant 7, 43 years, mother)

Wynaden (2007:32) identified four main reasons why family members caring for a relative with mental illness were committed to their caring role. Family members had an obligation to care, they owned their difficulties, they had to protect vulnerable members, and they were self-reliant. They provided physical support in terms of food and rehabilitation to their sick family member, along with financial support (Mokgothu, du Plessis & Koen, 2015:55). They simultaneously had to take care of their own physical and financial needs as well.

- **Family members experienced the need to provide better security**

During the interviews, most participants explained that they felt safer if their relatives with mental illness were being taken care of when they were at home. However, they felt uneasy when the relative with mental illness was being cared for by other family members. One participant reported:

*“A ni pfumeli leswaku a famba famba ni nga switivi, karhi unwana a ni pfumeli leswaku a huma.”* (“I don’t allow Sister M to leave home alone.”) (Participant 1, 60 years, brother)

Other participants stated that they tried to protect their relatives with mental illness from negative outside influences:

*“Ni kumeka ni ri kona laha kaya leswaku loko alava ku famba famba ni va ni ri na yena.”* (“I stayed fulltime here at home and when she wanted to go out I made sure that I go with her wherever she wanted to go”) (Participant 2, 53 years, mother)

During the interviews, participants raised concerns that they felt uncomfortable leaving their relatives with mental illness alone at home as they felt they were not safe and this became a burden to them. This was supported by the following statement from a participant:

*“Swona swa ni tikele heyi, ni fanele ku n’wi langutisa masiku hinkwawo ni vona leswaku u hlayisekini wadya wa hlamba wa mbala.”* (“To tell you the truth it was not an easy task to look after this person, I must see to it that she was safe, ate, bathed and dressed well.”) (Participant 2, 53 years, mother)

Other family members complained that caring for a relative with mental illness was challenging as they sometimes roamed around the village, asking for food from the community. This, in turn, resulted in the community bullying them and sometimes blaming the family for not caring for their relatives with mental illness. The following were some of the statements from the family members:

*“A ni koti ku tiendleala nchumu swo fana naku famba famba hi ku ni fanele ni va hlayisa hi masiku”* (“I can’t go anywhere to do my own things since I must take care of him.”) (Participant 3, 67 years, sister-in-law)

*“Mina ani swi kota kutitirhela hiku a ni tirha kwalomu mintini ya vanhu niti cleanela kwalomu majarateni ya vanhu kwahala location, se kulo na kumeka yena mikuma*

*kuri aswa ha koteki ku munhu aya ntirweni... munhu a boheka ku tshama kwala kaya a hlayisa nwana*” (“I am not able to work for myself, I used to work as a house helper cleaning peoples’ houses before she was born, but since she was born am not able to go to work because I had to look after her.”) (Participant 4, 50 years, mother)

The responsibility of caring for a relative with mental illness often falls on the family members. It has been reported that the reactions to or consequences of providing care made the caregiving role challenging, and it became a source of distress (Chang, Chiou & Chen, 2010:02). Taking on the role of caring for someone with a mental illness was a big commitment. It can be very emotionally and physically demanding, but it can also be a rewarding experience. Caring for a relative with mental illness gives the person their best chance of recovery. It is important to find out how to support someone with a mental illness, to get as much information as one can about their illness, to be open and honest with them at all times, and most importantly, to look after oneself (SANE Australia, 2018:8).

#### **3.4.2.2 Theme 2: Family members experienced that their relative was not mentally stable as evidenced by erratic behaviour**

The family members understood that relatives with mental illness were mentally unstable, as evidenced by their behaviour. They walked around asking for food from other people, even when they had enough to eat at home. Relatives with mental illness changed their moods frequently and acted inappropriately. During the interviews, one family member reported that their relative with mental illness locked himself in his room for more than a week and refused to speak to anybody during that time.

- **Family members experienced that their relative with mental illness had childlike behaviour**

The behaviour of the relative with mental illness not only affects the family but also other people, including community members. The people who were disturbed by the relative with mental illness included family members, neighbours, and community

members. Relatives with mental illness often displayed behaviours that were not normal, like behaving in a way that is only acceptable for children.

The disruption occurred in different settings. Relatives with mental illness sometimes displayed childlike behaviours towards their caregivers or the community. During the interviews, participants reported that their relatives with mental illness sometimes went around other people's families. Others picked things up in the road and brought them back to the house and played with them. All these behaviours were seen as being childish. Participants explained:

*“Phela Buti X I munhu loyi a vabyaka miehleketo loko u nga n’wi rhumangi ku hlamba anga hlambi, hinkwaswo I fanele ku n’wi rhuma”* (“The truth is that Brother X will never do anything on his own, you must send him to take a bath and other things.”) (Participant 2, 53 years, mother)

*“Swona swa ni tikela hiku hey! I fanele I n’wi languta masiku hinkwawo I vona ku wa hlayiseka, wa dya, wa hlamba I hanya kahle I kota na ku languta na timhaka ta mavabyi mayena.”* (“It is very difficult to live with this person, it is my responsibility to see to it that he eat, bath and is always safe.”) (Participant 3, 67 years, sister-in-law)

Another participant reported that his relative with mental illness behaved like a five year-old child. She changed her mood inappropriately, and the participant related the situation as follows:

*“Sesi M va languteka va ri va kulukumba kambe swindle swa vona swifana na swa nwana wa ntlhanu wa malembe.”* (“Sister M is an adult but her behaviour is equivalent to a child of five years.”) (Participant 1, 60 years, brother)

Another participant also elaborated:

*“A swini khomi kahle nwana mhani, nwana loyi ni nwu rhandza ngopfu and ni ringeta hi matimba ku nwu endlela swilo hinkwaswo leswi a swi lavaku and yena anga le ka swona, ma tiva loko mo nwu vona loko a kwatini la kaya leswi ani*

*langutisisaku xiswona, minga chava na mi byela. ...xikandza xa yena lexi xi va xi ri na anger yinwani a humesa na matihlu onge I mbuti vayisweke na ti mhondzo, ya tlhela ya tshuka yak u juuuuu.*” (“am not comfortable with this my sister, I love this boy very much and I try my level best to give him whatever he want but he does not see it. If you can see him when he is angry here at home, the way he look at me you can be scared. He has this anger face with red eyes and I cannot stand it.”) (Participant 6, 43 years, mother)

Trondsen (2012:22) confirms that families were concerned about the behaviour of their relative with mental illness and sometimes even feared their relative with mental illness' unpredictable and socially unacceptable behaviour. A study by Monyaloue et al., (2014:12) stated that family members caring for relatives with mental illness were concerned with some of the behaviours of their relatives with mental illness. These concerns related to verbal abuse, damage to property, poor personal hygiene and disrupting other people's lives, as well as roaming around aimlessly.

- **Family members experienced that their relative with mental illness had uncontrollable behaviour**

Family members related during the interviews that their experience in caring for their relative with mental illness was challenging. They indicated that sometimes they had to deal with difficult situations where they believed their relative with mental illness was misbehaving on purpose. Participants stated:

*“Buti X laha va tlelaku kona ka tika ku nghena kona, hi ku I munhu wo tsakimisa loko va tlele naswon loko va loloha ku ya e toilet na vusiku va ti kakela kwala ndlwini mi ta kuma va totele na minkumba loko dyambu rixa.”* (“The room that Mr X sleep in is not easy to enter. Sometimes when he is lazy to go to the toilet he will relieve himself there. In the morning his blankets are very smelly and soiled.”) (Participant 2, 53 years, mother)

*“Mara loko a sungula ku ya exikolweni, ive a sungula ku endla swinwanyani a kwata swinene a ticukumeta a va na matimba man’wani”* (“Everything started when she was about to start schooling. She will be very angry for no reason, hit

herself on the ground and became very powerful.”) (Participant 3, 67 years, sister-in-law)

*“Munhu loko a tshama na sesi M, u fanele a switiva leswaku va vabya miehleketo.”* (“When a person stays with Sister M, she/he must know that she is not mentally sound.”) (Participant 1, 60 years, brother)

Unusual or strange behaviour was described as any behaviour that was not appropriate to the circumstances. It occurred when a person was unnaturally moody, aggressive, euphoric, or mild-tempered. Relatives with mental illness frequently acted impulsively. According to Kay, Poggenpoel, Myburgh and Downing (2018:47), family members are unaware of the unpredictable behaviours that their relatives may experience. These behaviours often lead to confusion and the destruction of relationships between family members and their relative with mental illness.

#### **3.4.2.3 Theme 3: Family members experienced challenges in caring for a relative with mental illness**

The family members verbalised during the interviews that they experienced a lot of challenges while caring for a relative with mental illness. Most of the participants listed challenges such as financial challenges and caring challenges, which resulted in feeling obliged to care, and exhaustion. They also mentioned that there were rumours being spread by the community.

- **Family members experienced financial challenges**

Financial challenges were a concern for almost all the participants. They indicated that they had limited time to work and provide for the family as they had to look after their relative with mental illness. They shared that the small amount of money they earned was mostly from the disability grant for the relative with mental illness and the piece jobs they were doing. Some participants said:

*“Ni pfa ni lava mintirho ya nkarhinyana leswaku ni kuma mali yaku tatisa mudende wa yena hikuva na mina ni na vana.”* (“I have piece-jobs because when I look at

the money that Sister Maria is receiving meanwhile I also have kids' neh!")  
(Participant 1, 60 years, brother)

*"Liya ya mudende na yona a yilo tala ngopfu a ni R1700.00 a yi swikoti ku cover swilo swa lakaya hinkwaswo. Hi ku loyi a vabya."* ("The grant that she is receiving is only R1700.00 and it is not enough to cover all the expenses in the house.")  
(Participant 4, 50 years, Mother)

Financial constraints were reported to be the major challenge for most of the participants in providing support for their relative with mental illness. Some depended on child support grants as well as disability grants for their relatives with mental illness for survival, as they had no other source of income. Others were obliged to quit their jobs so that they could care for their relatives with mental illness. The following were the participant's words:

*"Mali ya vona ya mudende a yi talangi, a yi swikoti ku endle swilaveko hinkwaswo la kaya."* ("The social grant money is not enough for all our expenses with her at home.") (Participant 2, 53 years, Mother)

*"Hambi leswi a ka timhaka ta swakudya va katsiwaka swa kwala muntin mara mali ya vona yi fanele yi vona ku ya tatisa leswi xotaka."* ("When we buy food we include him, his money must be used to supplement the food.") (Participant 2, 53 years, Mother)

*"Loko Mkhengula va ha ri kona a va swi kota ku humesa mali ya ku hlayisa buti X, kambe sweswi va fanele ku dya leswi hidyaka swona"* ("When his mother was still alive, she used to give us money to support Brother X. Now we share with him what we have.") (Participant 3, 67 years, sister-in-law).

*"Leswi ni nga tirheki na kona tatana va la muntini va ngo ti holela mudende wa vona ani awulo tala se yaleyi ya Buti Magezi hi yona hitatisaka hi kota ku hanya."* ("My husband and I we don't work, my husband is receiving social grant. We use his social grant money to pay for other expenses.") (Participant 8, 67 years, sister-in-law)



Mokgothu et al., (2015:05) indicate that family members caring for relatives with mental illness need to be empowered, even though they had strength and were acknowledged for taking care of their relatives with mental illness financially, emotionally and physically. Family members caring for relatives with mental illness were often unable to generate an income and frequently had to rely on the financial support of the disability grant from the relatives with mental illness to meet their basic needs. They also used these grants to pay for any health expenditure associated with mental illness as they could not work and care for their relative at the same time (Iseselo et al., 2016:18).

Family members said during the interviews that they experienced a lack of support and financial constraints when the community and other relatives gossiped and made snide remarks or inappropriate comments in their homes whenever the relative with mental illness visited them. Participants reported that the grant money they received for their relatives with mental illness was not enough, yet most of them were unable to leave their relative and go to work. A participant said:

*“Ku fana na timhaka ta ku nwi hlayisa, swa timali...aswi olovi kahle...hiku ani na mina ani tirhi no tshama kwala kaya, ni nangutana na yena.”* (“Like the issue of taking care of her, financially is not easy, because I am also not working I just stay here at home looking after her.”) (Participant 4, 50 years, mother)

Some relatives with mental illness collected their support grants at pay points, and sometimes their family members accompanied them to collect the grants for them. These support grants were meant to maintain them and meet their basic needs. Some participants reported that they were happy because their relatives with mental illness received support grants with which they could support their family. Others claimed that support grants were not enough. Despite the money not being enough for the families, it brought some relief to the families. One participant reported that it was her sole responsibility to accompany the relative with mental illness to collect his money each month.

Social grants remain the cornerstone of the government’s key programmes to fight poverty afflicting children, people with disability, and older persons. According to South

African Government News (2013:14), since 1994 the social grants system has expanded from 2.7 million beneficiaries to over 15 million. Recent independent research results showed that the provision of social protection in the form of social grants had sustained many vulnerable households, particularly against the global financial crisis that threatened to reverse development gains in many developing countries across the globe (South African Government News, 2013:15).

- **Family members experienced caring challenges which resulted in feeling obliged to care and exhaustion**

During the interviews, most participants indicated that caring for a relative with mental illness was not easy and time-consuming. They stated that they found it difficult to care for a relative with mental illness and themselves at the same time. But they also said that they were willing to care for their relatives with mental illness for the rest of their lives.

This was supported by the following direct quotations:

*“Ni nga siteka nsati ni n’wi vustisile ku u ta swi kota ku tshama na munhu wa ku fana na sesi M.”* (“Before I got married to my wife, I asked her if she is going to be able to stay with this type of person like sister M.”) (Participant 1, 60 years, brother)

*“Mara N’wana wa mina ni ta n’wi hlayisa ku fika amakumu/maheteleleni”* (“But I will take care of my child to the grave.”) (Participant 2, 53 years, mother)

*“Ku sukela na loko mukhengula mhani wa vona va ha hanya, ava tshamela kuvula leswaku loko vo tshika va lovini ni sala ni vona ku n’wana wa vona wa hlayiseka”* (“When the mother was still alive she used to remind me that I must continue to take care of him even when she is dead.”) (Participant 3, 67 years, sister-in-law.)

In a review on the role of family carers in cases of severe mental illness, Rowe (2012:10) summarised the obligations of a family carer. He suggested that they provide

safe care as well as balancing involvement, risk management, information sharing, and knowledge acquisition. Providing care reduced carers' own free time and social activities (WHO, 2003:10; Fiorillo & Sabatini, 2011:5). It involved the emotional and physical work of sustaining caring, comfortable and loving relationships. It also involved more instrumental support, such as engaging in shared activities, accompanying family members socially, and to medical and support service appointments.

McCann, Bamberg and McCann (2015:04) relayed that carers found their roles emotionally and physically demanding. In their study, participants also shared that stress increased if their family member was heavily sedated or admitted to residential care. Increased levels of stress were also associated with criticism from other family members. Radfar and Fallahikhoshknab (2014:04) explored the experiences of family members caring for relatives suffering from depression and highlighted the economic and social costs of care.

Family members caring for relatives with mental illness sometimes experienced challenges and discrimination when attempting to engage with other members of the community (Iseselo et al., 2016:147). In this study, relatives explained that they were bound to stay at home and look after their relative with mental illness as it is not easy to go out with them and they did not feel they could leave them alone at home.

Participants explained:

*“Na tsandzeka na ku hlangana na va’nwana vatswatswi kuloni hi ku a ni munhu hi loyi la kaya I lava ku hlayisiwa.”* (“I can’t even go to meet with other women of my age group since I must take care of him.”) (Participant 2, 67 years, sister-in-law)

*“Loko ni kumile n’wana mina, a niboheka ku languta ngopfu n’wana ku tlula buti M” mara a swi nga ni oloveli hi mhaka ya mahanyelo ya vona.”* (“After giving birth to my firstborn child, things changed a bit since I had to care more for the child than him but it was not easy for me due to his behaviour.”) (Participant 2, 67 years, sister-in-law)

*“Aniku vani rhandza kasi ava ni rhandzi, se na va chava na sweswi, ho xewetana ntsena mara na chava ku ya ama kaya ka vona and vona va swi lava mina ana ha swilavi ku ya amakaya ya vona, ava tini sweswi loko Noel a vuyini va tlhela va lava ku vuyelelana ka mina mara mha na ha va lavi na chava.”* (“I thought they love me but they don’t love me, so am scared even now. We just greet each other but I am not comfortable in going to their houses even though they want me to come because I am now scared.”) (Participant 5, 68 years, mother)

This was supported by Rose (2011:12) stating that many families had the frightening experience of realising that they had no control over their relative with mental illness, especially if they were displaying unacceptable behaviour. Caregiving burnout is a state of emotional, mental and physical exhaustion caused by the prolonged and overwhelming stress of caregiving. While caring for a loved one can be very rewarding, it also involves many stressors since caring for a relative with mental illness is a long-term challenge; the stress it generates can be particularly damaging (Mark, 2013:4).

- **Family members experienced rumours which were spread by the community members**

Family members verbalised during the interviews that they experienced gossiping from community members as disturbing, and it was affecting them, especially since the gossip was also from close relatives. Participants reported during the interviews that community members made nasty comments about them as a result of being related to someone with mental illness. Other community members treated the relative with mental illness strangely whenever they came to their houses. This was supported by the following quotations:

*“Loko a kuma mi ri ku dyeni I ta fika a kombela swaku onge yena a nga dyangi nchumu, se mi kuma vanhu va vulavula swinene.”* (“Everywhere when she go and find that people are eating, she will ask for food as if we don’t give her at home. A lot of people complain about this every day.”) (Participant 1, 60 years, brother)

*“Xi nwani vanhu va hi vulavula ku biha ngopfu hi ku a va tivi leswi ni hlanganaka na swona laha kaya.”* (“People are talking a lot since they don’t know the challenges here at home.”) (Participant 1, 60 years, brother)

*“Swi endle leswaku laha mugangeni ni va ni nga ri kahle loko ni n’wi tshika a huma va twa I ngaku mehe no n’wi tshika ku ata vavisa kumbe ku chavisa vana vanwana”* (“I’m now a bad person here in the community, when I allow the child to play outside. They believe that I do it intentionally for her to hurt or scare other kids.”) (Participant 4, 50 years, mother)

*“Va n’wana va twa ingaku o ti edlisa o va munhu wa tinyimpi.”* (“Other members of the community think the child just behave like this because he likes fighting.”) (Participant 7, 43 years, mother)

Family members caring for relatives with mental illness experienced stigma from the community in the form of isolation, community neglect, labelling and stereotyping. Family members heard nasty comments from the community as a result of being associated with a person with mental illness (Nxumalo & Mchunu, 2017:208).

#### **3.4.2.4 Theme 4: Family members experienced coping strategies in caring for a relative with mental illness**

Coping strategies were an important aspect of caring for a relative with mental illness. In this study, participants showed a narrow range of coping strategies for dealing with their relative’s disruptive behaviours. During interviews, participants revealed that they prayed in order to cope with the situation of caring for a relative with mental illness.

- **Family members experienced support from extended family members**

Some participants reported receiving assistance from extended family members; for instance, in one case the participant was being supported by his wife in looking after their relatives with mental illness. Another participant reported that her siblings were supportive of her and her relative with mental illness:

*“Wansati loyi hi yena loyi ni vulavulaku hi yena neh! Leswi vulaku ku ku ya hi mina hambu no fa, kuna munhu loyi a nga sala a hlayisa sesi M.”* (“This woman is the person that I am talking about neh! Which means according to me even if I can die, there is a person who can remain and look after Sister M.”) (Participant 1, 60 years, brother)

*“Vamakwerhu wa mina va swi tiva va ni seketela, na loko ni lava ku pfuniwa va ni pfuna”* (“My siblings know much about my challenges and they are even available to assist.”) (Participant 4, 50 years, mother)

*“va sesi wa yena va ringetile ku nwi teka kambe va hluleke ku n’wi hlayisa.”* (“My sister-in-law tried to take him from me but she failed because of his behaviour.”) (Participant 2, 55 years, mother)

*“Mara vamakwenu wa yena va swi amukela leswi a swi endlaku, va hela va swi twisisa ku oti vabyela?”* (“But his siblings have accepted him and what he is doing, they end up understanding that he is just sick.”) (Participant 5, 68 years, mother)

Distressed family members and close relatives were not fully aware or able to make decisions in crisis situations such as acute psychosis; thus, they needed guidance and advice in these instances (Zabow, 2008:13). A study by Iseselo et al., (2016:146) specifically examined differences in coping strategies among caregivers of different ages, ethnic groups, genders and education groups. They found some evidence that older people were more religious than younger adults. In this study, family members cited praying as a coping strategy in caring for relatives with mental illness.

- **Family members experienced coming to a realisation about the mental illness, accepting the reality that it was a lifetime situation**

Participants reported that they accepted their relative with mental illness because of their religious beliefs. This helped them in coping with the situation. Participants explained:

*“Ku hava loyi hi nga va tshikelaka yena, ni fanele ku vona leswaku va hlayiseka swinene”* (“I don’t think there’s anyone who can take care of him except me.”)  
(Participant 7, 43 years, mother)

*“Ni amukerile xiyimo nwana mhani hi ku ni swi vonile kwale swi nga sungula kona”*  
(“I have accepted this situation since I know where everything started.”)  
(Participant 7, 43 years, mother)

*“Hambi leswi munhu a pfaku a hlangana na swiphiqo lahaya na lahya mara ni ku yini? wa fanele I swi amukela vutomi byi ya emhlweni.”* (“Even though I have some challenges, I must just accept for life to go on.”) (Participant 3, 67 years, sister-in-law)

*“A rendzi ni ta ku yini noti kayakayela na swona ni ku I nyiko Xikwembu xingalo ni nyika na fanela ni n’wi kurisa ku emahlweni”* (“This is my gift from God, I must do everything within my means to take care of her forever.”) (Participant 6, 49 years, mother)

Croft (2013:03) stated that disbelief and denial were the first to appear, followed shortly after by blame and anger when a chronic disease was diagnosed. When someone became ill with a brain disorder like schizophrenia, feelings and emotions were not very different. The last reaction to appear was acceptance, where the person or family members accepted the illness which was often seen as proof that they were not going to fight against their diagnosis. Croft (2013:03) further said that accepting the reality of mental illness was a long process and it does not mean it reduced the frustrations which originated from unrealistic objectives. During the interviews, most participants reported that they accepted that their relatives had a mental illness and that their conditions were incurable. Most of the participants reported that praying assisted them in accepting the situation. Acceptance and praying were among the most frequently mentioned coping strategies by some of the participants (Iseselo et al., 2016:146).

Evidence suggests that caring can have a negative impact on carers’ social support and networking, an important consideration as support for carers may be a protective factor that helps to alleviate some of the stresses involved in their role (Magliano,

Fiorillo, De Rosa & Maj, 2011:184). According to Lawska, Zieba, Lyznicka, Sulek and Poltorakk (2006:12), relatives with mental illness expect to be noticed, accepted and sympathised with. A supportive and accepting environment is thus indispensable for the optimisation of socio-professional therapy and rehabilitation of the relative with mental illness.

### **3.5 CONCLUSION**

In this chapter, the lived experiences of family members caring for a relative with mental illness in Giyani, Limpopo province, was discussed. Research findings were explored and described. These accounts of experiences were supported by direct quotations from participants and literature control. Findings were presented on the lived experiences of family members caring for a relative with mental illness. In Chapter 4, the researcher makes recommendations to facilitate the mental health of family members caring for a relative with mental illness.





## CHAPTER 4

### SPECIFIC RECOMMENDATIONS, OVERVIEW OF STUDY, LIMITATIONS, GENERAL RECOMMENDATIONS AND CONCLUSION

#### 4.1 INTRODUCTION

In Chapter 3, the results of the research study were discussed. In Chapter 4, the researcher provides an overview of the study by recounting the research background, problem statement and the aim of the study. Specific recommendations for the family members caring for a relative with mental illness are formulated. Recommendations are described to facilitate the mental health of family members caring for a relative with mental illness. The researcher also reflects on the challenges experienced in the study.

#### 4.2 SPECIFIC RECOMMENDATIONS TO FACILITATE THE MENTAL HEALTH OF FAMILY MEMBERS CARING FOR A RELATIVE WITH MENTAL ILLNESS

The research findings from Chapter 3 indicated that the family members caring for a relative with mental illness require effective interventions. Specific recommendations made in this chapter provide possible suggestions for family members caring for a relative with mental illness.

**TABLE 4.1: SPECIFIC RECOMMENDATIONS FORMULATED FOR THE FAMILY MEMBERS CARING FOR A RELATIVE WITH MENTAL ILLNESS**

THEMES	RECOMMENDATIONS
<b>THEME 1:</b> Family members experienced being alert about the safety of their relative with mental illness	<b>RECOMMENDATION 1:</b> <b>Support of family members</b> - Providing family psychotherapy

THEMES	RECOMMENDATIONS
<p><b>THEME 2:</b> Family members experienced that their relative was not mentally stable as evidenced by erratic behaviour</p>	<p><b>RECOMMENDATION 2:</b> Facilitation of mental health education of family members</p> <ul style="list-style-type: none"> <li>- Empowering family members to manage uncontrollable behaviours</li> </ul>
<p><b>THEME 3:</b> Family members experienced challenges caring for a relative with mental illness</p>	<p><b>RECOMMENDATION 3:</b> Facilitating the mobilisation of resources</p> <ul style="list-style-type: none"> <li>- Financial assistance</li> <li>- Acknowledgement of own needs</li> <li>- Using family support that is available to relieve them when exhausted</li> </ul>
<p><b>THEME 4:</b> Family members experienced coping strategies in caring for a relative with mental illness</p>	<p><b>RECOMMENDATION 4:</b> Facilitating strategies to cope effectively with caring for a relative with mental illness</p> <ul style="list-style-type: none"> <li>• Health coping measures, such as: <ul style="list-style-type: none"> <li>- Taking time out</li> <li>- Recreational activities</li> <li>- Talking with someone</li> </ul> </li> </ul>

Specific recommendations are described in detail in the sections that follow in order to facilitate the promotion of mental health of family members caring for a relative with mental illness.

#### **4.2.1 Recommendation 1: Support of family members**

Family caregiving for relatives with mental illness is influenced by various factors such as political, socio-economic, and cultural contexts, as well as related policies and health services. Family members find it difficult to cope with caring for their relatives

with mental illness. It seems that family members have insufficient knowledge on how to handle their relatives with mental illness. This was observed by the researcher while spending time with the participants in the field and during their visits to the psychiatric hospital while their relatives with mental illness were admitted.

Neighbours and community members were important components of social support. The findings from this study suggest that a strong support system is critical in the care of relatives with mental illness.

However, a lack of this important component has hampered efforts to improve relatives with mental illness' condition, and is a drawback to the psychosocial rehabilitation of relatives with chronic mental illness. This argument was supported by findings from India, which revealed several difficulties being encountered by patients being cared for at home (Iseselo et al., 2016:12). The most important way to improve the social support system in Giyani, Limpopo province, is to integrate mental health into the primary healthcare system.

The following recommendations were made:

#### **4.2.1.1 Providing family psychotherapy**

Challenges with mental illness do not only affect an individual's family members caring for them but also friends, neighbours, co-workers and others in the community. When a patient is living in the community, family members often provide the majority of care and support they need; yet caring for a relative with mental illness can be very stressful and it is important that family members receive sufficient support from healthcare providers. Family members need to understand the symptoms of mental illness and its effects on the patients' behaviour. Family members also need to understand the importance of not being too critical or overprotective of their relatives with mental illness (Black, 2019:7).

#### **4.2.2 Recommendation 2: Facilitation of mental health education of family members**

Family members in this study stated that the behaviour of their relatives with mental illness was sometimes erratic, which made them feel ill at ease; especially when they had to leave them unattended for longer periods. Family members caring for a relative with mental illness voiced the burden of caring they experienced. Health professionals were often not fully aware of the negative impact of caring for a relative with mental illness on those providing the care.

The following recommendations were made by the researcher:

##### **4.2.2.1 Empowering family members to manage uncontrollable behaviours**

The burden of caring for a relative with mental illness has been researched. Family members caring for a relative with mental illness need to be educated on mental illness and how to identify symptoms of mental illness. This awareness assists family members in receiving the help they deserve in an attempt to decrease their burden (Lippi, 2016:32). Marimba-Dube (2013:79) states that psycho-education has shown to be effective for family support in schizophrenia in many settings (American Psychiatric Association, 2013:25). Psycho-education interventions use a systematic approach based on supportive and behaviour therapy approaches, with the emphasis on the needs of the family members and the relative with mental illness. The main focus of psycho-education is on increasing the patient's and caregiver's knowledge about the illness, which results in improved adjustment to the illness and improved communication and problem-solving skills (Mangliano et al., 2011). Lippi (2016:33) claims that family interventions are considered to be critical components in the treatment of mental illness. These family interventions have shown to improve communication between family members and their relatives with mental illness, reduce perceived family burden, enhance links with the mental health system, increase the rate of follow-up care and medication adherence, reduce the risk of relapse, improve remission of residual psychotic symptoms, encourage employment, and enhance social and family functioning.

### **4.2.3 Recommendation 3: Facilitate the mobilisation of resources**

Family members caring for a relative with mental illness provided significant services at home to their relatives who need their help. A lack of information and resources has always been an obstacle. Healthcare providers need to assist family members in mobilising their resources for them to be able to care for their relatives with mental illness. Resource mobilisation refers to all activities involved in securing new and additional resources. Resource mobilisation was critical to family members caring for relatives with mental illness in this study.

Participants verbalised that they experienced financial challenges, caring challenges that resulted in feeling obliged to care and exhaustion, as well as challenges with rumours which were spread by community members. Based on these shared experiences, the following specific recommendations emerged and they included the need for financial assistance and acknowledgement of own needs.

#### **4.2.3.1 Financial assistance**

Financial constraints were reported to be a major challenge for most of the participants in providing care and support to their relatives with mental illness. They reported being dependent on disability grants received by the relative with mental illness as they had no other source of income. There are legislative and financial provisions that exist to protect and provide support for people with mental illness. This includes legislative provisions concerning a legal obligation for employers to employ a certain percentage of people with disabilities – including mental disabilities – and legislative provisions concerning protection from discrimination solely on account of mental disorder. According to the report on the assessment of the mental health system in South Africa (WHO, 2007:16), there was no financial assistance or legislative provisions concerning mental disorders in Limpopo province. Therefore, the recommendation was that the legislative provisions be provided in Limpopo province as well. Family members caring for relatives with mental illness must also receive financial assistance as they are unable to look for work to support their families.

#### **4.2.3.2 Acknowledgement of own needs**

Family members caring for a relative with mental illness must be encouraged to take regular time out and make time to do things they enjoy regularly. They need to socialise, to talk about how they feel, and avoid bottling up feelings if they are sometimes frustrated or need support. Family members caring for relatives with mental illness must try not to do too much. They were also encouraged to be aware of their safety when caring for a relative with mental illness. Chang et al., (2010:14) state that family members caring for relatives with mental illness must be sensible about what they reasonably can and cannot do by trying to prioritise and organise what they need to do by making a weekly list which is realistic and fair. This includes time for themselves and others, as well as the person they are caring for. Health professionals often find themselves concentrating so much on treating a patient with mental illness, they forget about the needs and difficulties of the family members who care for the patient (Lippi, 2016:21). He further states that family members require advice surrounding how best to care for their relatives with mental illness to positively contribute towards maintaining their own mental health (Lippi, 2016:21).

#### **4.2.3.3 Using family support that is available to relieve them when exhausted**

The demand of caregiving can be overwhelming. If the stress of caregiving is left unchecked, it can take a toll on the caregivers' health, relationships, and their state of mind, which can eventually lead to burnout. Caregivers were advised to seek assistance from other family members in caring for their relatives with mental illness to avoid burnout. They were also told to spread responsibility by involving other available family members to help (Mark, 2013:4).

#### **4.2.4 Recommendation 4: Facilitating strategies to cope effectively with caring for a relative with mental illness**

Family members caring for relatives with mental illness experienced challenges. Some of these family members displayed strengths that help them overcome difficulties and grew even stronger in caring for their relatives with mental illness. In most cases where family members caring for relatives were unable to cope with their caring roles, their

relatives with mental illness tended to relapse. This indicated that there was a need to facilitate strategies to assist family members in coping with caring for their relatives with mental illness. The following healthy coping measures were recommended:

#### **4.2.4.1 Taking time out**

There are recommendations offering relaxation strategies to help family members caring for relatives with mental illness cope with their burden, but SANE, Australia (2018:9) indicated that family members needed to be taught about self-care strategies that they can use without taking valuable time out of their caregiving roles or money that they simply do not have. These strategies include visualisation and guided imagery, where the family member can find a calm, quiet space, take a few deep breaths to calm their mind and body, and spend time focusing on things that make them happy and forgetting about their caregiving role.

#### **4.2.4.2 Recreational activities**

Caring for a relative with mental illness can be emotionally and physically demanding. Sometimes the burden can become too much; to make sure that family members avoid burnout, they need to set aside time to spend with friends and family who are not involved and do things that they enjoy, like gardening, going to the movies, or exercising. When the family member caring for a relative with mental illness is in good spirits and feels refreshed, they are then able to provide better support for the relative with mental illness whom they are caring for.

#### **4.2.4.3 Talking with someone**

Caring for a relative with mental illness is not an easy task. Family members caring for relatives with mental illness require assistance in coping with their caring role. Health professionals have a responsibility to educate family members on different coping strategies, which include talking to someone about the challenges they encounter during their caregiving activities. According to Nasser-Hassan, Mohammed, Elsaner and Sayed (2011:808), talking to others who have the same role of caring for a relative with mental illness is very useful as a coping strategy. Family members caring for a

relative with mental illness are advised to find out about any local or online training courses for mental health carers and to join mental health support groups to meet other people in a similar situation. Family members are also encouraged to talk to their relatives with mental illness and set limits and let them know what they can do for them and what they are not able to provide. By doing this, the family is able to control the situation.

### **4.3 OVERVIEW OF THE STUDY**

The objectives of the study were to explore and describe the lived experiences of family members caring for a relative with mental illness and to describe specific recommendations to facilitate the mental health of family members caring for a relative with mental illness in Giyani Limpopo Province.

As described in the background of the study, family members caring for a relative with mental illness had the burden of caring for these relatives. Evidence from some developing countries showed that a higher prevalence of relatives with mental illness lived with their family members (WHO, 2011:42).

#### **4.3.1 Research method and design**

A qualitative, exploratory, descriptive and contextual design was used in order to capture the essence of the lived experiences of family members caring for a relative with mental illness (Creswell, 2014:126).

##### **4.3.1.1 Phase 1: Exploration and description of the lived experiences of family members caring for a relative with mental illness**

In Phase 1 of this study, the lived experiences of family members caring for a relative with mental illness were explored and described. Data were collected by means of conducting in-depth phenomenological interviews, observations and field notes. Trustworthiness is described as the quality of an enquiry to determine whether the findings and interpretations made were an outcome of a systematic process, and whether the findings and interpretations can be trusted (Lincoln & Guba, 2013:84).



Measures to ensure trustworthiness include credibility, transferability, dependability and confirmability (Lincoln & Guba, 2013:104). In this study, the researcher carefully selected participants on the basis of the varied experiences they could bring to the study. The researcher collected data objectively and analysed the data using Tesch's method of data analysis. An independent coder was used to increase the credibility of the findings.

While analysing the research data, four main themes emerged and were identified after data analysis. The first theme was that family members experienced being alert about the safety of their relative with mental illness. This theme thus indicates that family members caring for a relative with mental illness experienced frequent risk assessments of their immediate surroundings and the need to provide better security. The second theme identified was that family members experienced that their relative with mental illness was not mentally stable, as evidenced by erratic behaviour. This theme indicates that the relative with mental illness had childlike behaviour

The third theme identified was that family members experienced various challenges in terms of their caregiving role. The last theme explored that family members experienced coping strategies in caring for a relative with mental illness. Family members described different coping strategies which they used in order to cope with the burden of caring for a relative with mental illness in Giyani, Limpopo province.

#### **4.3.1.2 Phase 2: Specific recommendations to facilitate the mental health of family members caring for a relative with mental illness**

The findings of Phase 1 were used to formulate specific recommendations to facilitate the mental health of family members caring for a relative with mental illness. The following specific recommendations were formulated for the family members.

The first specific recommendation was to support family members by providing psychotherapy in order for them to cope with the burden of caring for a relative with mental illness. The second specific recommendation was the facilitation of mental health education for family members. The researcher believes that by empowering family members, they can be able to manage uncontrollable behaviours displayed by

their relatives with mental illness. The third specific recommendation derived from the findings was to facilitate the mobilisation of resources. The findings of this research indicate that family members require financial resources, acknowledgement of their own needs, and the use of available family support to help them when they are exhausted. The last specific recommendation was the facilitation of strategies to cope effectively with caring for a relative with mental illness.

#### **4.3.1.3 Achievement of purpose and objectives**

Results showed that providing continued care and support to relatives with mental illness is demanding and challenging for family members. There is evidence from around the world that family members are scantily supported in providing the care required by relatives with mental illness; this is because of communities' attitudes and beliefs, which frequently have an effect on the type of assistance that is provided to family members caring for relatives with mental illness.

The Theory for Health Promotion in Nursing (University of Johannesburg, 2017:1-8) was used as the paradigmatic perspective in this study. In line with this study, the results indicated how family members caring for a relative with mental illness experienced that their caregiving affected their daily lives. In conclusion, it could be stated that the objective of the study was met and led to the formulation of specific recommendations to support these family members. These specific recommendations serve as a useful tool for mental healthcare practitioners working with family members caring for a relative with mental illness. These specific recommendations can be used to guide and empower professional nurses, family members, community members, relatives, and other healthcare practitioners in assisting family members caring for a relative with mental illness.

#### **4.4 LIMITATION OF THE STUDY**

The following limitations were identified in the study:

Participants in this study were mostly female as there were seven females and one male. This can be an indication that women were more affected by the caregiving role.

The researcher also had challenges finding participants to be included in the study as most gave excuses when they had to meet for the interviews. The researcher had to follow some participants to their workplace for interviews as they did not have enough time at home after they left work.

The researcher had challenges obtaining approval from the Limpopo Department of Health to conduct the research, which led to delays in completing the study. Some families were also not comfortable being audio-recorded as they feared their recordings might end up on social media, and this could have exposed their situation to the public. The researcher reassured them and strengthened the privacy and confidentiality of their information.

#### **4.5 GENERAL RECOMMENDATIONS**

In line with the objectives of the study, recommendations for the family members caring for a relative with mental illness in Giyani, Limpopo province, were proposed. The purpose of these recommendations was to facilitate the mental health of family members caring for a relative with mental illness in this area. The recommendations are meant to be implemented by mental healthcare practitioners, particularly those working at the specific psychiatric hospital where the study was conducted.

These recommendations must be used in conjunction with the existing policies and protocols, and within the legal framework of the Mental Health Care Act No 17 of 2002, in order to more effectively support family members caring for a relative with mental illness. These recommendations were made with specific reference to nursing practice, nursing education and nursing research.

##### **4.5.1 Recommendations for psychiatric nursing practice**

From the study results, it is clear that family members caring for a relative with mental illness need professional help and support. Psychiatric nurse practitioners play an important role as they come into close contact with the family members and their relatives with mental illness. During this stage, they are able to assess the needs of family members and support them.

The following recommendations are identified for the psychiatric nurse practitioners:

- Identify and assess the needs of family members caring for relatives with mental illness.
- Provide health education to family members, especially about mental illness, its effects and possible coping mechanisms.
- There is a need for public education, and this could be done in the form of frequent mental health awareness campaigns targeting schools, clinics and churches in the community.
- Media as a means of communication could also be utilised to educate the public about mental illness.

Psychiatric nurse practitioners should address the challenges of family members who feel incompetent, and strengthen the families who are competent in giving care to their relatives with mental illness. This can be done by offering health education at hospitals or clinics according to the needs of the family members.

Psychiatric nurse practitioners should take responsibility to educate the community about mental health and mental illness; for example, by offering mental health awareness campaigns.

#### **4.5.2 Recommendations for psychiatric nursing education**

Topics such as the lived experiences of family members caring for a relative with mental illness, should be included in the nursing curriculum at training schools, as well as the effects of mental illness on family members.

Skills to be covered include how to handle an aggressive mental healthcare user, who to call, where to refer the relative with mental illness, as well as the rights of MHCUs.

All nurses working with psychiatric patients must have basic training in caring for psychiatric patients in order to equip them with basic knowledge and skills in dealing with psychiatric patients and families.

### **4.5.3 Recommendations for psychiatric nursing research**

It was clear from the findings in this study that there is insufficient literature about the lived experiences of family members caring for a relative with mental illness in Giyani, Limpopo province. Therefore, the researcher recommends that more research be conducted on the lived experiences of family members caring for a relative with mental illness, especially in Giyani, Limpopo province.

### **4.6 CONCLUSION**

While this is a small scale study, that focused on the lived experiences of family members caring for a relative with mental illness in Giyani, Limpopo province, it provided important insight into the lives of family members caring for a relative with mental illness. Those family members who participated in the study by sharing their realities, hopes and interactions, made the issues they face in their everyday lives a little more visible. Where there is more visibility, there is a hope of appropriate intervention and support. Their involvement and engagement with the research process are indicative of the role they play in advocacy, and a reflection of their objectives to pull apart obstacles for those who follow in their paths. The range of experiences and issues raised throughout are complex.

UNIVERSITY  
OF  
JOHANNESBURG

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## Annexure A: Ethical clearances



**FACULTY OF HEALTH SCIENCES**

**RESEARCH ETHICS COMMITTEE**

NHREC Registration no: REC-241112-035

REC-01-02-2018

15 August 2018

TO WHOM IT MAY CONCERN:

**STUDENT:** SHIMANGE, ME  
**STUDENT NUMBER:** 800801755

**TITLE OF RESEARCH PROJECT:** The Lived Experience of Family Members Caring for a Relative with Mental Illness

**DEPARTMENT OR PROGRAMME:** NURSING

**SUPERVISOR:** Prof M Poggenpeel **CO-SUPERVISOR:** Prof CPH Myburgh

The Faculty Research Ethics Committee has scrutinised your research proposal and confirm that it complies with the approved ethical standards of the Faculty of Health Sciences, University of Johannesburg.

The REC would like to extend their best wishes to you with your postgraduate studies.

Yours sincerely,

A handwritten signature in black ink, appearing to be 'C Stein', written over a horizontal line.

**Prof C Stein**

**Chair : Faculty of Health Sciences REC**

**Tel: 011 559 6564**

**Email: [cstein@uj.ac.za](mailto:cstein@uj.ac.za)**



**FACULTY OF HEALTH SCIENCES  
HIGHER DEGREES COMMITTEE**

HDC-01-71- 2018

30 August 2018

TO WHOM IT MAY CONCERN:

**STUDENT:** SHIMANGE, ME  
**STUDENT NUMBER:** 800801755

**TITLE OF RESEARCH PROJECT:** The Lived Experience of Family Members Caring for a Relative with Mental Illness

**DEPARTMENT OR PROGRAMME:** NURSING

**SUPERVISOR:** Prof M Poggenpoel **CO-SUPERVISOR:** Prof GPH Myburgh

The Faculty Higher Degrees Committee has scrutinised your research proposal and concluded that it complies with the approved research standards of the Faculty of Health Sciences, University of Johannesburg.

The HDC would like to extend their best wishes to you with your postgraduate studies

Yours sincerely,

  
\_\_\_\_\_  
Prof H Abrahamse

Acting Chair: Faculty of Health Sciences HDC

Tel: 011 559 6550

Email: [h.abrahamse@uj.ac.za](mailto:h.abrahamse@uj.ac.za)

## Annexure B: Limpopo Province Approval Letters



LIMPOPO  
PROVINCIAL GOVERNMENT  
REPUBLIC OF SOUTH AFRICA

### DEPARTMENT OF HEALTH

Enquiries: Stander SS (015 293 8650)

Ref: LP\_2018


Shimange ME  
University of Johannesburg

Greetings,

**RE: The lived experience of family members caring for a relative with mental illness**

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
  - Research must be loaded on the NHRD site (<http://www.nhrd.hst.org.za>) by the researcher.
  - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
  - In the course of your study there should be no action that disrupts the services, or incur any cost on the Department.
  - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
  - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
  - The above approval is valid for a 3 year period.
  - If the proposal has been amended, a new approval should be sought from the Department of Health.
  - Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.

  
Head of Department

  
Date

Private Bag X9302 Polokwane  
Fidel Castro Ruz House, 18 College Street, Polokwane 0700. Tel: 015 293 6000/12. Fax: 015 293 6211.  
Website: <http://www.limpopo.gov.za>

*The heartland of Southern Africa – Development is about people!*





**LIMPOPO**  
PROVINCIAL GOVERNMENT  
REPUBLIC OF SOUTH AFRICA


**DEPARTMENT OF HEALTH  
MOPANI DISTRICT**

Ref: S4/2/2  
Enq: Mhlati IE  
Tel: 015 811 6543

To **Shimange ME**  
**University of Johannesburg**

**Re: PERMISSION TO CONDUCT RESEARCH IN MOPANI HEALTH FACILITIES: YOURSELF**

1. The matter cited above bears reference
2. This serves to respond to the request submitted to research on the topic: "The lived experience of family members caring for a relative with mental illness."
3. It is with pleasure to inform you about the decision to permit you to conduct research at Evuxakeni hospital within Mopani District.
4. You will be required to furnish hospital authorities with this letter for purposes of access and assistance.
5. You are further advised to observe ethical standards necessary to keep the integrity of the facilities.
6. The Mopani District wishes you well in your endeavour to generate knowledge.

  
Director: Corporate Services  
Date: 16.06.2019



**LIMPOPO**  
PROVINCIAL GOVERNMENT  
REPUBLIC OF SOUTH AFRICA

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**DEPARTMENT OF HEALTH  
EVUXAKENI HOSPITAL**

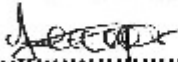
Ref No : S4/2/2  
Enquiries : S Chuma  
Tel Extension : 2017

To : Shimange ME  
University of Johannesburg

Dear Madam

**REQUEST FOR PERMISSION TO CONDUCT RESEARCH IN MOPANI HEALTH FACILITIES:  
YOURSELF**

1. Your above-mentioned request has reference.
2. Note that your request was granted to conduct research at Evuxakeni Hospital on the topic  
**"The lived experience of family members caring for a relative with mental illness"**
3. Note paragraph 5 of the approval letter for your attention and compliance.
4. Also note that further arrangements should be made with the relevant section/s of the hospital for assistance in consultation with the responsible manager/s.
5. Thanking you.

  
.....  
**HEAD OF INSTITUTION**

13-08-2019  
.....  
**DATE**

## Annexure C: Participant Information Letter

### DEPARTMENT OF NURSING RESEARCH CONSENT FORM

#### LIVED EXPERIENCES OF FAMILY MEMBERS CARING FOR A RELATIVE WITH MENTAL ILLNESS

Please initial each box below:

I confirm that I have read and understand the information letter dated 20 July 2018 for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

I understand that my participation is voluntary and that I am free to withdraw from this study at any time without giving any reason and without any consequences to me.

I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Name of  
Researcher

**DEPARTMENT OF NURSING RESEARCH CONSENT FORM OR INTERVIEWS TO BE AUDIO-TAPED**

*(Please delete this entire page if your research does not involve audiorecording)*

**LIVED EXPERIENCES OF FAMILY MEMBERS CARING FOR A RELATIVE WITH MENTAL ILLNESS**

Please initial each box below:

I hereby give consent for my interview, conducted as part of the above study, to be audio-taped.

I understand that my personal details and identifying data will be changed in order to protect my identity. The audio tapes used for recording my interview will be destroyed two years after publication of the research.

I have read this consent form and have been given the opportunity to ask questions.

\_\_\_\_\_  
Participant                      Signature of Participant                      Date                      Name                      of

\_\_\_\_\_  
Signature of Researcher                      Date                      Name of Researcher

## **Annexure D: Permission from the nursing manager to conduct research**

### **DEPARTMENT OF NURSING REQUEST TO CONDUCT RESEARCH**

July 2018

The Hospital Management  
Evuxakeni hospital  
P/bag x9661  
Giyani 0826

Dear Sir

I Mihloti Eunice Baloyi [Shimange], hereby request to conduct a research study on “The lived experiences of family members caring for a relative with mental illness” at Evuxakeni Psychiatric Hospital in Giyani. In order to comply with the requirements for Masters of Science in Psychiatric Mental Health Nursing at the University of Johannesburg. This study will be done under the supervision and guidance of Professor M Poggenpoel and Professor CPH Myburgh.

I therefore kindly request that the unit managers of the mental health ward contact families caring for relatives with mental illness admitted to the hospital to invite them to participate in my research. The unit managers then can provide me with the family members' contact information who are willing to participate, so that I can make an appointment with them to arrange for interviews.

#### **THE OBJECTIVES OF THIS RESEARCH STUDY ARE:**

1. To explore and describe the lived experiences of family members caring for a relative with mental illness in Giyani.
2. To formulate recommendations to facilitate family members' mental health.

For these objectives to be achieved, a qualitative design which is exploratory, contextual and descriptive in nature will be used. The number of participants in this study is not specific but will depend on data saturation as evidenced in repeating information.

Interviews will be conducted with individual participants at their homes. The interviews will last for 40-60 minutes. The participants will be requested permission to audiotape the interview. The data will be kept under lock and key in the researcher's office. Only the researcher and supervisors will have access to the data. The data will be destroyed two years after publication of the research.

Participation is voluntary and they may withdraw from the research if they wish to do so without any penalty. The results of the research will be made available to your institution as well as to the participants on request.

I will be delighted to answer any further questions about this research study. If you have any question regarding this study feel free to contact me at 0849920646.

Regards,

Mihloti Eunice Baloyi Shimange, RN, B Cur ed Admin [PHC],

Alternatively you may contact my supervisor:

Marie Poggenpoel RN; PhD, fANSA

Professor; Department of Nursing

Tel: 011 559-6686

Email: [mariep@uj.ac.za](mailto:mariep@uj.ac.za)

You may also contact my co-supervisor:

C P H Myburgh, BSc Hons, M.Comm, D.Ed, DHE

Professor Department of Educational Psychology

Email: [chrism@uj.ac.za](mailto:chrism@uj.ac.za)

If you feel that any questions or complaints regarding your participation in this study have not been dealt with adequately, you may contact the chairperson of the faculty of the health sciences research ethics committee at the University of Johannesburg:

Professor Christopher Stein, e-mail: [cstein@uj.ac.za](mailto:cstein@uj.ac.za)

Tel: 011 559 6564



## Annexure E: Example of a transcription of an interview

### Uj Research Interview Transcription 06 Venue: Xikukwani Village

Researcher	Loko mi ri na vona la kaya, mi va mi.....i yini lexi mi hlanganaka na xona, swi va swi ri njhani aka nwina loko mi tshama na yena la kaya ate Taniya akha a vabya mavabyi lamaya?
participant	Loko ha ha ku nwi teka ahinge hi te hi ta nwu teka ani,
Researcher	Uhhm!
participant	Hi ta fika hi tshama manharu,hi tshama masiku manharhu mune swiri kahle, ra vu 4 swi jikini
Researcher	Uhmm!
participant	Ahaha hlanganani,wa hlanganani was ungula ku hlasela la kaya wa rhuketela loko a vona vamakwenu vile, loko a vona mina ana ha ri kahle na mina no khoma mbilu hiku na tiyisela
Researcher	Uhmm!
participant	Anga ta na kwala kusahani afika ani rhuketela,anga kona makwenu wa kona lowu nwani loyi I nwana wa ndzisana ya mina loyi
Researcher	Uhh!
participant	Loyi anga te Minjhani mipfukini I va tukulu va kona I nwana wa sesi wa kona
Researcher	Uhh!
participant	Ande futhi luya I nwu rhandza ngopfu luya
Researcher	Uhh!
participant	Uhmm, I tintwsalo I tekiwe hala ka kheyi, luya .....loko a vuya aku malume na famba, yindlu ya yena hi leyi ya noel
Researcher	Uhh!
participant	Ita ku nwana sesi I famba kahle iva hi luya afamba
Researcher	Uhh!



participant	Se ti pfa ti hundzulela loko a vona vamakwenu lavanwani a caca, loko a caca a katsa na mina loko a caca a katsa na mina, se ani vamakwenu lava ava swi tivi
Researcher	Uhh!
participant	Wunwani loyi a tlela ka yindlu leyi I nwu bini
Researcher	Ehh, wa ba na ku ba?
participant	Se ani lembe leriwani
Researcher	Uhh!
participant	Swi ndli leswi yena aaaa a tirhisa kamara yinwani lani se a ku anga yi lavi se hinkwaswu ha pfumelela na leyi na le ndzeni ka yindlu leyi ina kamara
Researcher	Uhmm
participant	Se a cinca aku leyi new mhani ani yi lavi himhaka yaku hi le patwini na rhaseriwa acinca aya le
Researcher	Laughing
participant	Se makwenu wa kona avuyini ari lani swa lembe rinwani leswi ni swi vulaku
Researcher	Uhmm
participant	Ivi aku muxee, muxee!se loko a ku boti aku huma la ivi a huma a yima laa
Researcher	Uhhhh!
participant	Ivi a sungula ku caca akatsa na mina aku I teke hi noyi
Researcher	Iri mi ednle yini?
Researcher	A ca acaca a hlambela nhlamba ya xisati a katsa na mina se loyi a hlamula aku why boti va endla so?
participant	Uhmm
Researcher	Aku u teki noyi, a rhuketela a rhuketela,boti a thuketela boti luya se a kwata kwalanu, loko a rhuketela a endla sweswo se luya a huma ata hala a fika aku boti fambani ku tleni aku ndhlidhlimbeta a fika aku bvheve a mubedweni a tlela
participant	Noel?

Researcher	Uhh noel.ivi noel aku indla mina leswi avuya aku ani endliwi hi mufana mina, mufana ila ku vona yini namuntlha, wa delela mfana hi loko va yimisana lahayani
participant	Uhmm
Researcher	Loko va yimisana ni fika ni nghena xikarhi, na swi vona ku ku se va lava ku lwa
participant	Va la ku lwa
Researcher	Ivi a ni khoma hi voko aku wena mukhegula ndziwena yimela lee!, himpela ni chaja ni ya lee, loko tiku i
Researcher	Uhh
participant	Ti sungula ka nwana mhani mihlolo leyi ninga yi vona
Researcher	Uhhh
participant	Ma tiva vahimana lero nata himana va nyika va nyikana va nyikana va nyikana ivi a vuya a ku nsaaa! Lowo vabya loyi
Researcher	Uhmm!
participant	Ivi lowo hanya kahle a kandziya ivini ku hooo, hi swona mi ta dlaya munhu loyi
Researcher	Uhh!
participant	Iva se kwalanu swi hela aya nghenu lomu a tlela iva luyani a rholela swi swa yena kuna swinwani ava nyikanini
Researcher	Uhh!
Participant	Loko ri xa nampundzu aku “muxe”, aku “boti”, “tisa swilo leswiya nwana mhani, swi herini
Researcher	Uhh!
participant	Swi herini laughing
Researcher	Swi herini ku kwata lokuyani
participant	Haa ma tiva mihlolo leyi ni kombiwku yona nwana mhani, mha ni swi tivi ku wsi huma kwihi
Researcher	Eish!
participant	Ivi ke! ha hundza ka xiyenge xexo
Researcher	Uhh!

participant	Sweswi a vuyini I endle sweswo, kuna kufana wunwana anga kona la mpfhuka ahuma na mpundzu
Researcher	I nwana wa nwina?
participant	Ehh! Mheee...ni tevule hi nhwanyani, ivi ku ta hwenyani, kuta noe hilonkulu, ivi kuta mufana, ku ta mufana, kuta mufana, vafana va mina va ku 5 loko tlhandlama noel wa mufana I lovini.
Researcher	Ok
participant	Se va sala va ri vangani, va sala va ri 4 vafana, va nhwanyana va ku I 2
Researcher	Uhh
Participant	Vanhwanyana a ku ri 2 ntsena
Researcher	Ok
participant	Vafana va mina va sala va ri 4 kuri ku ava ri 5and hiku landzelelana vafana lava
Researcher	And noel hi yena wo sungula
participant	Ehh I tlhandlama loyiwani, I tekiwe kunwani hala vukatini
Researcher	Uhhh
participant	Se hiti tshamela ,na yena yaloye va lwini lembe ra ku hela
Researcher	Uhh!
participant	Mativa lokoa yima lee a teka ribye ari aba munti lowu,fasitere leriya ringa pfuriwa lahaya mari vona iri fayini, ivi mhani lavaya va ku nar lava fasitere ra mina
Researcher	Eish!
participant	Ehh! Iva hi ya hi ya xava, la hile ndhuneni la
Researcher	Ok, ka ndhuna xikukwani?
participant	Ehh!va seketela hosi xikukwani, la hile ndhuneni hi tenga kona milandzu (swinwani aswi nga twali kahle hi mhaka ya moya) ivi ndhuna leya la yiku nwana wa nwina wa hi rhasela, nwana wa nwina mhani wa hi hlambela a ttheleli kwale a vaku ari kona,ivi se ni foyinela hahani wa yena va ta
Researcher	Uhhh!

Participant	Ti fika ti tengiwa va ku .....hahani va ku ani munhu loyi wa vabya na, ma swi tiva kun a manese yanwani aya nga ri kona ma ye a vuxakeni, sweswiwani se hita endlisa ku yini hiku Noel wa vabya va ku nwu tlheriseleni lomu ari kona hina a hi nwu lavi .....
Researcher	Hi sweswa December ya leya sweswi?
participant	Iswa lembe leriya I swa December ya lembe leriya iswa makhalenyana
Researcher	Ok I swa khale nyana
participant	Ehh! Vaku hina nwana loyi ahi nwu lavi, aminwu lavi nwina vaku ehh niku I yini ka mhani, hi loko va sala va famba vanhu lavayani lowo tlhandlamana na Noel loyi aku se I yini ka Noel nwana mhani tana haleni kaaa! Nwana mhani I nga ha rhuketeli. Aku iri yini!"iri yinii!, a nwu sukela loko a nwu sukela ma tiva va banana xibakela xinwani la ndhzaku ka yindlu leyi mativa swi nghena laa.loko va banana xibakela ivi lava lahaya muntini lowuya va nghena vaku munhu loyi ihi rhuketela masiku hinkwawo hikahele, boti wunwani wa lahaya I ze a nwu ba Noel
Researcher	Boti luyani aba Noel?
participant	Aba Noel, ati ze ti lava ku endla milandzu lembe ra kona kwala xibedlhele xa Nkhensani loko a sungula ku hlanta ngati a sungula ku...nkhensani yi kwata hinkwayo na madokodela vaku mhani khomisani , pfulelani mufana loyi I vavise nwana wa nwina ni kun a swi vona Noel a anga pfumeli aku mhani minga nwu khomisi a ni swi lavi
Researcher	Uhh!
participant	A ala, hi leswo Noel I humini la aya patwini va kha va rhuketelanana mufanawa lahaya muntini lowuyani, ivi se aku ahi hlangani va hlangana kasi ivi ni badama a henhla ka mubedwa ni ku nilava ku ta swi vona kahle ani humi, ite na nhonga yo tani afika aku teka ni ku nyikka, teka niku nyika, aku nsaaa! Aku gogogogoro loko ni huma la "niku vuya ita hetisa" aku "ninge nwu hetisiiii, I loya nwana wawena I vuloyi bya wena"

Researcher	Va rhuketela na nwina?
Participant	Ehhh! Mina ana ha laviwi hi munhu ndhawu leyi nwana mhani, mha naha fambi niya mintini ya vanhu lomu, ku sukela loko Noel a vuyini a hamba rhuketela, loko a yima hi lhayani arhuketela loko a yima hi hala a rhuketela mhani lowa la, a jika a rhuketela munti
	lowu a jika a rhuketela munti lowu a jika a rhuketela munti lowuyani, a jika a rhuketwla munti lowu, mi kuma ku vanhu vanga ha ni lavi, niku jhii! Mha ni nga swi tivi ku wa tshama na vanhu tikweni va ngaku lavi kasi vutomi byi tani,ni vhela ku sukela siku rero ni ku swi mphuuu ni ti tshamela kwala kaya ri za ri pela xa mhe iku suka ni ya kerekeni, sweswi a vuyini ani yangi kerekeni va swi tiva na le kerekeni niku loko ni teke munhu wa mina luya mita, ni khongerisa Kunene hiku ina ni vona Noel ku I endlisa ku yini hiku ita sala a banana na vama kwenu loko vani vutisa le ninga nwu veka kona va ta ku awu yi kwihi ni ta vula ku aniyi kwihi hiku vutomi bya Noel lebyi a hanyaku byona na byi tiva ku I hanyisa ku yini ( aswi twakali kahle hi huwa ya moya lowu awu ri ku beni).....sweswi a rhuketelana na luya wo tlhandlama a nga nwu tlhandlami, I ntsanana ngopfu, ata a fika a yima laa aku aw uvula yini,aku swilo yini ivi niku ha nwu tshiki mani akuri wa vunharhu niku ani mundzuku na nwu fambisa na, kuri madyambu yakona malamo I cace a caca lero hi nela, kuna swilo swinwani la a swi chayisaku I swa yena haaa! Noel I fayetele swilo swo tala nwana mhani la muntini lowu loko Noel ani swi tivi kuri swilo leswi swi huma kwini nwana mhani nila ku swi twisisa ani swi tivi ku swi huma kwini, papa yena va love hi 2000, 2001 ni hluvula nala wa papa yena. 1, 2, 3 ka nhweti ya vu 3 noel akhomiwa hi mavabyi lama ari ka 8 axikolweni.
Researcher	Ok maha kunwi sungula hi 2001
participant	Ehh!papa yena loko va lovini
Researcher	Uhhhm!

participant	Uhhh! Se mhani swi tivi ku Noel swi ednlisi ku yini, Noel I fambisiwini tindhawu hinkwato, na mhani wa mina van i vitanini ninhuma ka mninginisi ni nwana w aka mninginisi, mhani lucy nyambilavayani I nwana boti.
Researcher	Na va tiva hi tirha na vona
participant	Haaa! Hi pfunana na mhani hi kayakaya a tshunguriwa swi tsandza, kokwani wa yena va nwu teka va nwu yisa hala shivulani
	a tshunguriwa swi ala, tindzhawu to tala ni nghaneni swi tsandza se loko ni ri na vadokodela ku fana na sweswi lembe reri vani byerini vaku mhana Noel, ari le N1. Va ku Noel namuntlha I tlhelela avuxakeni, ni ku “miri yini?”
Researcher	Ari kwi, a suka kwini? A suka a Nkhensani?
participant	A Nkhensani, lembe ra ku hela khisimusi I dyele a Nkhensani,loko yiku mmm.....january Noel a susiwa a Nkhensani, a yisiwa N1,
Researcher	N1 yile kwihi?
participant	Lahaya phakathi lahaya la vuxakeni laa! Lahaya....
Researcher	Ohooo! Aka ward leyo sungula leya le vuxakeni?
participant	Ehh! A nghanisiwa kwalahaya Noel, a tshama
Researcher	Leyiya yi khiyiwaku?
participant	A tshama noel a tshama ni khan i ya pfluxela ni ya pfluxela ivi kwalaya ka February, ni vuye ni ya nwu teka hi February na mudende wa yena anga holangi a tshovelele card swi sweswo a cukumeta lee! Ivi van i nyika yena hi fika hi humesa lahaya hi humesa rinwani khadi hi humesa mali.....se loko hi vuya lakaya hi fika hi tshama aya holi mavabyi yoya yak ha ya nyanya. Noel o cacisa sweswo o huma a teka mali liya a fika ayi hoxa lee akha a huwelela aku naku vona ku wa vilela “teka mali ya wena msathanyoko ndzi wena” akuri R1300-00 ni teka mali liya ni bohela nkhanwini, aaa no vona swi mpfumba noel a ya kha a nyanya, ho za hi lava movha hi nghena laa, loko hi nghena laa o teka ni ku nyika

Researcher	A ba nwina?
Participant	Hiswona, ni pfa ni biwa ivi se hi nwi boha mavoko na milenge hi nwu rhwala hi nwu yisa kwale, swi endlise sweswo ivi loko swi endlise sweswo a fika le loko ari lahaya vaku nwana wa nwina se I tthelela le ari kona a vuxakeni.niku ihi naa? Va ku ehh! Se vaku mhana noel amina ku vilela naa? Hiku nwana wa nwina hambu hoteka makhadi hi languta ka noel aka ha cincu nchumu vutomi bya yena hinkwabyo, kasi se ava ni byela lembe ra vumbirhi vat
	shame vani byela lembe rinwana madokodela va ku Amukelani hambu mo nwu teka noel mikha minwu tshungurisa noel I xisweswi mo amukela aku nge cincu nchumu mito heta mali.
Researcher	A nge he holi
participant	Va ku noel I ta tshamisa sweswi madokodela van i hlamuselini va ku Amukelani vaku amina xivilelo kamnhani? Ni ku hi yini, ni ku hi mali ya mayelana na noel? Niku hambu no vilela mali ya noel, noel I tshame ngopfu. Xexi ano dya xona noel ari laa ni ta dya xona, mina ni tsakela noel a hanya a kha a hlayiseka a ri kwale mina ni tata ni ta nwu pfuxela. Hambu no rilela mali ya noel noel anga ri kahle akha a xaniseka kaya, akha a endla xihlekisi vanhu vakha va nwu bukutela ni kha i kun i tshamela mali ya noel aswi nge ni tsakisi, va ku muis ma swi tiva ku ya pfariwa ni ku anina problem xexi a ni dya xona loko ni nwu veke ku sungula ni ta dya xona, noel ava ari laa so langa a hlayisekini ni tata ni ta nwu pfuxela mina mhani wa yena ani na problem.
Researcher	Se sweswi vavava vayi pfarini mali liya?
participant	Eh! Yi pfariwini mali ya noel
Researcher	Hikuva a tthelele a vuxakeni?

Participant	Ehh! Ve ri idya yona kweleni, very yi tirhela kwaleni.mina madokodela ni va hlamule sweswo se ani swi tivi ku dokodela Ntshana na dokodela Nkuna ava lava kuni pfuna njhani,mina ni hatle ni va hlamula ku mina anina problem ntsena loko Noel a hlayisekini mali ya noel hambu leswi ayi ni pfuna kwala ayi ni pfuna kona mara loko noel a nga hlayisekangi a swi khomananangi na swona
Researcher	Uhhh!
participant	Maswi vona, swi khomananini?
Researcher	Aswi khomanangi
participant	Ani rhandi mali ku tlula vutomi bya yena mina noel a ni nwu rhanda inwana wa mina and ni nwu rhanda ku fana na vana va mina kinhwavo mara lexi xinga nghena ka noel mina ani xi tivi.ani xi tiv xo tiviwa hi xikwembu ntsena ku mavabyi lama noel mati hi
	kwini ku swi sukela kwini swi ya kwini swo tiva hi yehova ari kaya a tilweni
Researcher	Mi ri swi sungule loko ka ha ku hluvuriwa swa papa?
participant	Ehh!
Researcher	Mara aku na lexi minga xi vona ku xinga va xi vange mavabyi kumbexana?
participant	Lexi ninga xi von aka Noel, Noel I boxini siku rinwani, kokwani wa yena ava tirhisa yini, kokwani wa yena ava byale nsinya leee! La kaya le masinwini lee, wu kula wu fika kunwani la swihi tumbelele nkarhi wo leha hi nga tivi nchumu kokwani wa yena ava ri na xilo xinwa xo chela la, xo leha xaxikhale, ma swi twisisa? swi swa vanhu va khale swa ku va chela la va mpompa va mpompa ahinghena kwala hi va hleka hinga swi twisisi ku mukhegula lava va dyaha yini.and va dzaha xilo lexi va tlele na vana lava la ndlwini
Researcher	I mukhegula
participant	Ehh! Mukhegula wa nwinyi wa munti lowu
Researcher	Ohooo!



participant	Vakha va tlela na vana lava la ndlwini papa vona ava tirha a joni, va ze siku rinwana va vilela papa vona va ku he wena.....va ku why mhani vatlela na vana lava la ndlwini kuriku vana lava iva kulu
Researcher	Ava tlela nava Noel?
Participant	Ehh! Na va given na vanwani.....va tlela la ndlwini, and ava tlharihini vanwani va nga va ringana na mufana loyi mingo I chike laa. Se nwinyi wa vana a gungula aku hay mani Nwa-Risenga vana lava va kurini va fane va huma le va ya tlela ka yindlu yinwani, kuriku mukhegula lava xi xexiya ava kha va xi koka hina ahi swi cheki ku I yini kasi akuri mbangileyi vayi tirhisaku la ndlwini mukhegula lava, se hi loko loyiwani ayi dzondza I swi boxinisiku rinwani aku mheni dzaha fole phela kokwani ava tirhisa mbangi, aku kokwani ava byale mbangi le masinwini, niku ni tshama ni swi vona mara ani nga swi tekeli nhlokweni
Participant	Aku haa swi sukela kwalani ni yi dzahe ngopfu
Researcher	Leswi vulaku ku mavabyi lama ma nga va ma sukele kwalaya ka mbangi leyi?
participant	Manga va ma sukele kwalahaya ka mbangi lahaya ka noel hiku mavabyi lama leswi manga fikisa swona ka noel ro sungula I kalakalini a tlele ka leyi yindlu mina ni tlela ka liyani, marha mina ani nwu twangi, kulo twa hi lava lahaya muntini lowuyani va ta hiku tsutsuma va ku "mhani mjaji mhani mjaji noel wa kalakala aminwu twi naa"? ni huma niku mina ani nga nwu twin a kokwani wa yena va huma va ku ahinga nwu twi, niu swi yo yini noel aku mhe ni vona vanhu vani vitana, ni teka noel ni nwu yisa aaa kunwani ka Mkhabele hala ni nghena kona kereke ya apostole va fika va nwu khongelela va ku fambani mi ya tlela, hi famba hi fika hiku hi vuya la kaya ava akha a dyondza xikolo swi ya swi kha swi ya ehh na mavabyi maya makha ma ya mahlweni
Researcher	Ma kha ma ya mahlweni?
participant	Ehh! Aza a famba aya tshama kwale muntini wa lowuyani va kha va nwu khongerisa, uhhh! Nihlangene na yaleyo mhaka ya noel

Researcher	Se mara loko ava a vuyini ka fana na sweswi hi December ari kona iva akha a endla yini loko ari kwala kaya?leswi aswi tirha tirhaku/
participant	Loko a vuyini Noel la kaya leswi aswi tirhaku-tirhaku na swi dyana-dyanani,I tolovele kuu..mhane ni lava tiya ya muhavulu, I tirhisa tiya ya muhavulu kuri "Five Roses" a endla mati lamaya a kha a nwa mari weak, akha a nwa akha a nwa a nwa niku wena tiya leyi aku hayi mhane ni twa yiri kahle, kuriku hala tlhelo akha a tirhisa na yini, na fole leriya rati draw, eh akha a tirhisa rona sweswi hi dyambu a tirhisa fole kumbe a heta ra R10.00 kumbe a tirhisa tinharhu hi siku
Researcher	Uhh!
participant	Ehh! Kambe mbangi anga ha dzahi, loko wi pfumela a pfa ari tshika nkarhi lowuya ari la kaya aku ehh, anaha dzahi mina akha a endla sweswo, ehh! And se loko swi nga ri kahle I to pfuka ito
	pfuka a endla sweswo loko swi fika kwalanu mi kuma na ku loko se swi la ku pfuka na vuswa anga.....
Researcher	A nga ha pfumeli ku dya
participant	Uh-uh! Anga ha pfumeli, na nyoka loko yinwu dliva aya ku phalazeni, aya ku phalazeni, na sweswi ite nwhe mhani mina himpfhuka ni vuya la kaya ni lo ya a toilet masiku mambirhi, niku I ri yini? Aku nilo ya masiku mambirhi, ni ku why? Aku hay aniswi tivi. Na vuswa se anga ha dyi kahle hiku loko se mo ze ma sungula mavabyi ma yena na swakudya anga ha dyi kahle
Researcher	Se mara hiku vona ka nwina mitwa hingaku loko a vuyini ani miri I fika a tshama nyana masiku mambirhi manharhu ari kahle ivi swi pfuka ami hleketi ku kumbe angava a yi kuma mbangi leyi a tlhela a dzaha? ami hleketi ku kumbe anga va a yi kuma mbangi leyi
Participant	Hay! Ani I tshama ari yexe landlwini mina ni ri kumbe I fole reriya a fostelaku ku fambani miya ni xavela mina ni ri hi rona ri pfuxaku mavabyi kumbe hi rona ani swi tivi.

Researcher	Se mara nwina mimi ti twa nhjani loko ava a ri kona, ami chavi ku anga tshuka kumbexani ami vavisini
Participant	Ahh! Na chava no xiyaxiya loko a vuyini ahitlela la nyangweni la
Researcher	Se ami tleli ndlwini?
Participant	Eh-eh rivanti a ni ri tshikisa swesiya ive hi tlela laa! Ani na vana lavanwani ava ri kona, ehh kuna siku leri iii I vusiku bya yini I vusiku bya khisimusi aku ila ku tlela kwala handle ii I nyuwere(new year) a ku namuntlha ani tleli a tshama kwala a kha a caca loko a heta o tlela kwalahaya se na vana lava va kha vaya va ku ka boti kaaa, va khongotela
Researcher	A caca aku swi lo yini?
Participant	O caca aku nwina na magoya ya nwina mina amini lavi, I caca mina aku na swi vona ku amaha ni lavi futhi sweswi swi swa kona swi endliwe ngopfu ku swi kombetela mina, aku mina amaha ni lavi mi lava vana lavanwani, niku mina ani lavi vana lavanwani ni
	mi lava hinkwenu. Ni ta ku zondela yini? Loko ani ku zondha awu ta swi vona hi mintirho hi kun ale vuxakeni mina ani nga ta ya
Researcher	Ami nga taya, mita ngopfu hey loko hi cheka lahaya mi ta kahle
Participant	Nwana mhani na ta and ni ta himbilu ya mina hinkwayoo!futhi hambu voni byela ku sweswi loko ni nwu vuyisa va ku hina hi ta ze himi pfala la mara a va endlela ku yena ava kahle a swi twisisa ku loko vo lava ku ni pfala kuni nga ha ti va nga ni pfala.....sekova ku hay sweswi se ni pfumele ngopfu sweswiya loko mini phonela ani ta van i rile ngopfu ahi ri ku tirheni hala
Researcher	Ok
Participant	Se swi kuma ku jehova wani kotisa ivi niku haa! Ni phonela hi vanwani va le xibedlhele ivi ni ku mhe na famba vari swi nga endleka ku va ta kaya, ivi va ku haaa fambani se va vtheta va hi chucha hinkwenu
Researcher	Haa ni vuye ni vona ku ninge ti hi ku mi te mile ni nga lavi kumi tsutsuma-tsutsuma

Participant	Ehh!ni lokombela hi suke hi 3 loko hi suka lee
Researcher	Haa loko anilo swi tiva inge ni tinvhete ni ta
Participant	Ni ni ni mbhazini la phonini la
Researcher	Ok hi mhaka yak u ni mi phonele hi phone ya xibedlhele
Participant	Hooo ayi nga ha khomiwi himunhu and himpela
Researcher	Ehh akuri phone ya xibedlhele liya
Participant	Hoo ani ku hi letaka nwina se ni ku aredzi ni ta vona hi swona
Researcher	Hu-uhh...se mi vulavula hiku ami pfa mi rila se mi ti twa njhani nwina loko mi va mi ri ka xiyimo lexi?
Participant	Xa Noel?
Researcher	Uhh!
Participant	Sweswi ni swi amukerini, ani nge se amukela loko ni tshama ni khan i rila
Researcher	Ami nge se amukela?
Participant	Ehh se nilo khongoteriw hi vamhani va kereke loko hi famba swikohngelo swa va mhani sweswo Taniya se ni pfani yima ni
	hlambuluka ni vulavula ni tsundzuka kunwani ni vulavula leswiya swi ma swi tiva ni za ni thinthana na munhu la ndzeni la ivi vaku (phone ya vona yi rila ivi va hglamula). Mativa hi ri xikhongelweni aku ri tikweni rale ka mbatlu
Researcher	Uhh!
Participant	Maswi tiva munhu loko I hlambhunuka hi munhu, ni twa munhu loyi anga ndzeni a mi controller va suma tinghoma ivi ku suka mhani wunwani nivulavula niheta ni tshama hansi, aku mhani minga ha vulavuli xikwembu xirilo xa nwina xi swi twini mi rila ngopfu namuntlha, ni swi twa ku and I vula swona aku na siku na rinwe minga ha nwu khombeledi, nwina mo khongela ntsena swirilo swa nwina xikwembu xi swi twini
Researcher	Uhhh xi swi twini
Participant	Uhhh ni swi twa ku I vula swona, ni ti tshamela, swo tsandza hi pfa hi famba hi minti ya hina leyi hikha hi kombela mikhongelo
Researcher	Uhh!

Participant	Hi kha hi khongerisana se ani mhe swi fika laa ( va vula mali) hi nga ku kumi se ani loko va ta va lava mi fane mi lava ahinge xinkwa, na ti tiya
Researcher	Hoo va lava ku dya, va lava ku fika va dya loko va fika
Participant	Ehh!loko mi heta ku khongela mi fane mi va endlela swakudya vadya, se mina swi ni tsandzisa sweswo se ni ku hay va ku aredzi mitava mi mi ta ndla siku rinwani loko mi ri na yona
Researcher	Uhh!
Participant	Se ni swi teka hi moya wa kahle, iku khongela swi nga ni endlela niva kahle ani nga pfumeli,sweswi ani fane ni khan i rila laaa, ni kha nimi rilela nwina,se nale xibedlhele ava hamba vani tshinya vaku minga rili, Amukelani na nwina mi ta vabya hlayisiwa hi mani, xibedlhelel xaha ri le Nkhensani lee va ku loko mi hamba mi rila ahi swi tivi ku Noel ita hlayisiwa hi mani hiku hina hi vona nwina mhana yena laa ahi se vona munhu wunwani ata ata nwu vona
Researcher	Uhhh! Loyi ataku ata nwu pfluxela
Participant	Ni swi vona ku and himpela ni twa ni hlayisekinina mhe nwinyi, ni twa ni hlayisekini nwana mhane hiku la misaveni ano ti guarantee hilero ni twa ni swi kota ku ti endlela swilo hinkwaswo se niku hey xikwembu lexi na xi kulu ka mina hi kun i twa naha hlayisekini ka swinwani, ehh! Swinwani swa mavabyi yo karhi ni twa na hlayisekini
Researcher	Maha hlayisekini
Participant	Ni ti khome kahle ka swinwani se ni twa ku ey!xikwembu lexi na xikhensa himpela inge ni biwe hi stroke himhaka ya nwana loyi
Researcher	Himhaka ya noel
Participant	Se ni twa hinkwaswo swesweo naha amukerini ku xikwembu xaha ni khome kahle kun i kota ku pfuna Noel
Researcher	Uhh
Participant	Maswi vona?
Researcher	Uhh!ok mara swi swi swi kahle loko mi hatle mi amukela

Participant	Ehh!
Researcher	Uhhh! Se mara mi vona hingaku kuya amahlweni mingava mikha mi la ku pfuneka njhani?
Participant	Aka Noel?
Researcher	Aka Noel?
Participant	.....uhh ni vona ingaku anga pfuneka kwalahaya anga kona na mina ni tata ni ta nwu pfluxela kwalahaya, ani rileli mali ya yena ani mali ya yena yi nwu hlayisa ari kwalaya, ni nge vuli vamakwenu wa kona vakha va tirha-tirha sweswi va xavaku hi swo hi nga ta dya swona loko a sungula ku endla sweswo phela Noel miehleketo ya yena yi 'ormal" (normal) ku hlaya ka vanwani va ku Noel I tlharihe ngopfu, se swi nwu vangela xikhutu ku swiri mhani va dya mali ya mina va kha va dya na va makwenu leswi vanga nwu endlisa swona a miehleketweni ku a zonda vamakwenu wa yena yinga nwu vangela problem aku swiri mali ya yena nay i tirhisa loko yena ari lee, se mina ani na problem ni twa a hlayisekini, a hlayiseka kwalahaya sweswo Taniya , se ani
	tivi ku ri ku himavonele ya nwina ami vula hi mayelana na yini?maswi vona
Researcher	Uh-uh! Ano lava ku tiva matitwelo ya nwina naku mivona ingaku minga pfuneka njhani, mi nga nwu kota ku tshama na yena ani hileswi hi lavaku ku tiva swona
Participant	Haaa....ku tshama na yena Noel ehh hiku ani ipfa aaahi jikela kwala , ni vula ku hi 2011 loko...tati wa yena lonkulu mhani wa nhwenyani luya anga mi hawuza luya, ilo mi hawuza hi ku ahi ku mi xeweta leswiya ani swi lavi
Researcher	Laughing, hay... I vana va masiku lama

Participant	Hay ani swi lavi mina....se mhani wa yena l vuyini hi 2011 a vabya ari joni, se loko avabya ari joni swi kuma ku and loyi (noel) mi nwu discharging le vuxakeni, aku “ka mhani, kasi mile kwini? Amiti mi ta ni teka mina ni horini”ivi ni ku “Noelle mina anile kaya” yindlu leyi yi sala yi endliwa swilo leswi hinkwaswo mina ni nga ri kona ni lande tati wa yena a joni
Researcher	Ok...l vabyele joni?
Participant	Ehh! i vabye ari joni ati tirhela ajoni axavisa tjara sweswiya swo Taniya, (talking to her grandkids)...se ni kumeka kwalanu hi ri joni hikha hi xavisa akha a ku ka mhani kaa amaha ni lavi ni ku nwanango nile joni ni ta vuya. Nita vuya ni ta ku teka mina ani le kaya ni le joni, kasi tati wa kona vo abyisa ku yini..... (talking to grandchildren)
Researcher	Greeting the grandchildren
Participant	I mativula ya uh...ya yena sesi luya l ma tivula ka mhani wa yena
Researcher	Ok
Participant	Ehh ku ta nhwenyani wunwani anga kona laa va sukini na xihlanginyani xinwani xa mufana.
Researcher	Ok
Participant	Ehh se swi vuya swi endlisa sweswo se hi ye hiya vuya nhweti yi herini se loko hi vuyini ni ku ka hahani, ka hahani ni ta va kota vanhu vambirhi mina naa? Se va vuya va ku hay mhani mjaji fambani miya nwu teka, ni ta avuxakeni ni fika ni nwu sayinela a vuya la kaya, ari kahle njhani! VA makwenu wa yena lava, haa ari kahle ngopfu and nkarhi wa kona aha dzaha mbangi, aha yi dzaha.
Researcher	Ok, loko a fika la kaya a fika a dzaha?
Participant	A dzaha mbangi, loko avuya ahayi dzaha, haa...sesi wa yena avabya aza a tilovela ari kahle munhu wa xikwembu na vanhu loko va nghena ava xeweta, ivi swi yaku hi tshamini nkarhi lowo leho ari kahle, haa... l vi swi yay a “thokomuku” haa l ncini hi nga xi vona

Researcher	Aku ri lembe rihi loko ku...leswi mi swi vulaku?
Participant	Aku ri lembe leriya ra uhhh...ni ta vutisa loyi kumbe na yena rivele
Researcher	Greeted by one of the patient's younger brothers.mara loko ari xibedlhele I I I tikomba a mi tsakela ngopfu I tshama akha a vulavula hi nwina musii
Participant	Loko ari xibedlhele kun a siku leri loko ani byela swilo ahi ngo ani byela swinwani aku "ka mhani kasi mi ta ni teka rini?"Swi ta jika kwalanu, ni ku ani na khan a ta ni ta ku pfluxela kwala xibedhlele, aku ni vula kaya kun i ta vuya rini? Haa! Kwalanu hi ta holova va za vaswi twa lavaya ivi va lamula nyimpi yakona niza ni vuya kaya, ita sala a kwatini na mina ni vuya ni kwatini. Mara siku rinwani loko ni ta a tsakini I to fika a hlekelela swi va kahle.
Researcher	Uhh!
Participant	Ko fana na tolo, phone leyi a phona hi yona iya mani? Ya nwina?
Researcher	Eh-eh! I ya kwalaya xibedlhele
Participant	I phonini iri aka makwenu wa yena wa rikitse anga kona laa, hi loyi mufana loyi ava lava ku jikelana
Researcher	Uhhh!
Participant	Uh! Loko a ri...mufana wa mina wa rikitse iii anga kona laa, I tirhela kunwani kwahala Giyani mara xa ha ri xitsongo ani I I xifanyetani axa ha dyondza xikolo, xi tirhela aaaa...very hile carwash?
Researcher	Hile carwash .ku hlantswiwa ti movha.
Participant	Se kwalanu aku kaa...I teki phone ya yena yinwani anwu nyika se aku ini xavela phone, tolo ani byela swona aku ka mhani xihola hi ti 15, se aku loko a hola Isaac mi nwu byela ani xavela phone, ani xavela ni ku ina ni ta nwu byela, se tolo ni nwu byerini niku hey I I ringeta ku xava phone. Iri hambu y ova na xirhedionani so. Mara ita faya



Researcher	Ang ...nkarhi wunwani mi kuma ku ange fayi hiku mikuma kuna yaleyi minge I phone hi yona tolo,I ya vavabyi kuloni kwale xibedlhele
Participant	Eh!na swi tiva iya vavabyi kuloni
Researcher	Se va lombana se loko nwina mi nwu nyika mali, mali liyani va hakela
Participant	Se mali yinwani ni yi siyini, ni yi siye ka sister ntimbani siku leriya ni nga nwu heleketa yi ri R30.00 se va ku hita yi teka hiyi yisa a xiphazeni
Researcher	Ehh ku loko a lava ku xava aya aya xava
Participant	Eh va vurini va ku vata sala va nwu nyika se ni ku haa aku na problem mi ta sala mi nwu nyika se vava ya ya nwu vekela se hiswo sweswo leswi swa Noel leswi a hanyisaku swona
Researcher	Mara loko ari le xibedlhele Noel I rhunga na tintanghu musi, na mina I ze a ni rhungela tintanghu
Participant	Ehh! End swi kahle leswi aswi endlaku
Researcher	Se loko ari la kaya iva a a a a nga koti ku...anga swi endlil anga koti ku swi endla?
Participant	Anga endlil, I kota sweswo nwa muhavulu na ku tshama
Researcher	Iva alo tshama dyambu hinkwaro?
Participant	Ehh! Alo tshama kwala ndlwini, loko a swi lava a pfala yindlu a endlil sweswiya ati tlelela
Researcher	Dyambu hinkwaro?
Participant	Eh! Siku leri hi ngo vusiku hinkwabyo anga tlelangi, I tlele dyambu hinkwaro aya aya pfuka namadyambu, nikha ni ku yooo ahinge tlele. Haaa otlhe loko a pfuka aku mhane hambite I lava yini ivi aku nilava ku ya tlela nwina mhani mina namuntlha ani lavi
	huwa ya munhu, a vtheta aya ti tlelela ni za yi xela sweswa I nyuyere.anga ha , hi nga ha nwu twangi huwa ya yena
Researcher	Mara aku na tipilisi leti avaku ati nwini?
Participant	Ita twa mani, na tona ati herini teta chukele,ava pime tipilisi tinwani aku hey leti ti ni helerini

Researcher	Ok ina mavabyi ya chukele hala tlhelo?
Participant	Uhh ku nghene na mavabyi ya chukele
Researcher	Se loko ari la kaya I vona hi mani ku wanwa mapilisi
Participant	Loko haha ku vuya ita ni vitana aku mhane, ni ku hwee!aku tanani mita vonaminga ta ku ani nwi,a nwa na mundzuku ita ni vitana aku tanani mita vonaivi a nwa, na mundlwani ani vitana aku tanani mita vona lamanwani swi ta hundza anga ha ni byeli swi ta hundza ni nga ha swi voni
Researcher	Laughing anga ha mivitani
Participant	Ehh, ni to vutisa ku minwini aku eh! Eh ita endlisa sweswo iviswi hundzisa sweswo ana ha swi voni ku I nwise kuyini, se hambu hi kwala mapilisini ani swi tivi.
Researcher	Ok, hey...yaa! mina ani lava ku...ni le ku...hi le ku lavisiseni ku loko vari makaya va hanyisa ku yini na nwina mi va miri kerhi mit I twa njhani loko mi hanya na vona
Participant	Ok...
Researcher	Ehh! Ngopfu-ngopfu na ku sweswi ani ava vuye amakhisimusini.
Participant	Ehh!
Researcher	Se hiva hikha hi lava ku vona ku loko ari kaya wa hanyeka ku anga kota ku vuya ata tshama la kaya naa!
Participant	Haa!anga hanyeki, anga nantirhisano
Researcher	Mara vamakwenu wa yena va swi amukela leswi a swi endlaku, va hela va swi twisisa ku oti vabyela?
Participant	Va va swi twisisa loyi ningo I lwe na yena se va swi twisisa,loyi ani I tshama joni anga se swi vona otwa loko hiku makwenu wa wena I endlisa ku yini
Researcher	Uhh! Hi kona a kotlana na swona sweswi?
Participant	Hi kona aswi vona sweswi, iku va langusanini va langusana ivi aku se I zama ku endla yini se ni swi vona ku hoo, luya I ta ku I na loyi se aku I, ni ku hay! Nwu sukeleni, se maswivona ku loko no famba ngopfu swi nge lunghi?
Researcher	Swi nge lunghi

Participant	Ehh! Swi nge lunghi,
Researcher	And ava swi koti ku loko vava vari kona va tshama va bula tani hi vana va munhu wunwe?
Participant	Ehee... ava swi koti swi lo ze swi endla hi lowunwani makwenu wa kota aya aya bula na yena, siku reri ningo a tshame laa!ehh!ava nwu landzelerisi ngopfu, kumbehi swona swi endlaku mina ani swi tivi,
Researcher	Na yena anga swi koti kuti tshineta ka vona
Participant	Eh-eh, loko o nghena kwala ndlwini I nghenini, se loyi siku anga vuya I nghene kwala ndlwini kwala va tshama nkarhi wo leha va kha va hlekelela swinwe.swi va kahle ani ava ha ku vuya swi va kahle
Researcher	Uhhh!
Participant	Se loko ri xa masiku hinkwawo aku Minjhani ka boti, aku hipfkukini Minjhani, ni pfukini Minjhani sweswiya swo taniyani.
Researcher	Ehh!
Participant	Maswi vona
Researcher	Uhhh!
Participant	Uhh!
Researcher	Hay...ni ta fika ni nwu hlamusela na yena ku ani yini kaya,
Participant	Se mina ani swi tivi hiku siku leriya loko hi fambini la ani yena a fostela ku ita vuya
Researcher	Aku ita vuya kwini?
Participant	Aku ita vuya kwala kaya se a a alava ku faya swilo swinwani swa yena ani veke lahaya ndlwini, se niku Noele ni landzelela hambal alava ku ya chela a toilet. Ni xavelela niku hita vuya swinwe
Researcher	I yinin swilo leswi
Participant	Swo Chaya
Researcher	Ohoo! Sen aku ilava ku fayela
Participant	Hiku ani na ala mina nir mundzuku ninge vuyi na yena
Researcher	Ohooo...

Participant	Se ano xavelela niku hiri hita vuya swinwe se hi kona ninga ponisa swilo leswiya inge swi fayeteriwini.
Researcher	Laughing, se loko aswi fayini loko semiehleketo yi vuyini ava kahle anga ha swi lavi?
Participant	Wa swi lava a tlhela aku ka mhani kasi ni fayise kuyini?niku iyo fayetela,haaa I faye swilo swo tala ngopfu
Researcher	Uhhhh!
Participant	Niku ilo faya mhane hay...mha ni swi tivi
Researcher	Se loko mi nwu hembela loko se aya fikale vuxakeni anga va nga na problem?
Participant	Ah! A kwatini se vaku swi nge tirhi ani va fike vanwu humesa se ni sala ivi van i vutisa ku mi tshamise ku yini na Noel, se ni hlaya hinkwaswo, eh hinkwaso ku Noel a endla leswi na leswi hiku ini kume nit shame halahayaaa, afika aku ehhh! A fika a yima la ninga kona aku “loko ni swi lava ninga mi khisa nwina, ni nga mi khisetela ni mi khisetela” se ni ku “mina kiii? Aku eh, ni ku hay. Ku endleka yini hi wena ka Noel? A hleka a suka lani nga kona se niku hayi se kulava ku nghena moya wanjhani kwala ka v aka hina kwala ka mufana loyi, hiku vanhu vat shame van i dyondzisa swinwani le a admitiwe kona,va ku mhane hina hi mi tsundzuxa swinwani, Noel lomu xibedlhele loko hi nwu amukerini la Tsakani vanwani va rapiwa hi vana va vona lava miehleketo lava va nga vuli,and loko va kha va vabya mavabyi lamaya makulu lamaya va cheriwa mavabyi va chava ku vula se ni mina niku hay vana va mhani mina ninge chavi sweswo, ni ngo namba ni vula xikanwe loko ni nga ha nwu lavi kaya ni vula ive nwina mina tshungula ivi yena a tshama kwala anga ha vuyi nale kaya ka mina ku tlula kun i tshama na nwana wa mina ni tlhe ni fa na swona swo va yini mara?vaku hey vanhu votala la, va ku mhana Noel, sister vanwani va tirhela halaya ma va tiva vo tshuka,va ku

	hina ahi lavi kumi hembela vanhu vo tala va onhekini lava nga na vana, hina hi hlamala nwina, va ku vanhu vo tala va cheriwe mavabyi hi vana va vona va chava k uvula and loko se swi ya boxeka va ku l vana va hina hinga tshama na vona mara loko va ha va raper ava vuli.mina ni ku mhe ninge vuli niku mhe ninge chavi ani mani twa sweswi ni ri ite ni nga mi khisa ni ku ikhisa mina wena na?
Researcher	Eh! And hey
Participant	Ni ku l khisa mina niku futhi van i byerini ku ninga fihli, ni vurini , na va Mabasa ni va byerini nava Sister Ntimbani ni ku aniloko mih dyondzisa mi ri hi nga fihli leswi hi endlwaku swona
Researcher	Uhhh!
Participant	Loko hi ri na vona kaya hi fihla yini na swo va yini?
Researcher	Uhh!
Participant	Se mha ni swi tivi ku kumbe va chava ku poyileka aka vanhu mhe ni nge cah ani ango ti endlisa o vabya.
Researcher	O vabya
Participant	Se mhe ninge pfumeli ku tshama na nwana wa mina ni ku loyi ani rhipi hiku wa vabya se mhe ni ta tsham na yena hay!ni nge swi koti
Researcher	And loko mi swi tumbeta nwina mi nga vuli yena l ta vheta a tshama akha aya mahlweni a endla swona.
Participant	Va kha va ndliwa votala na kwala tikweni va kona halaya ntsungeni le, mhani wa kahle l ze a nwana wunwani a dlaya kokwani wa yena va fini sweswi va celeriwini swi na malembe...sweswi l tshama na mhan yena mhana kona ang achavi anga vuli, mara tiko ri kha ri swi tiva ku kambe mukhegula luya l tshama na nwana wa yena nay he l ta nwu dlaya
Researcher	Uhh! loko se a karhele l ta va dlaya

Participant	Ehh! Hiku na kokwani wa yena I va dlayini hi sweswa masangu, ani swi vekiwu hi xikwembu ku ri swilo leswi swi fika la swi yimiku, ku loko I ri mukhegula swilo leswi aswa ha endliwi, loko I ala endliwa wa dlayiwa swa ku dlaya, maswi vona, haa mina ni nge
	civi nwana mhani ni mi byela swi suka mbilwini.... (Inaudible) ehh! hi ku ani aswi pfuni nchumu, iti vangela mavabyi I nga ri na mavabyi
Researcher	Hiku loko mi fihla mi ta tsandzeka na ku ya kamberwa na ku nyikiwa mapilisi yo sivela mavabyi
Participant	Se mina ni chava swona ma swi vona, ndzhaka lembe ra ku hela ni vuye ni suka ni ya clinic na sweswi ni ta kuma siku ni ya. La clinic ya lahaya kusahani na Nkhensani hospital, ni kuma sister wunwani niku hay...nwina sesi mina ni kamberwa na mavabyi, aku “ ami chavi ka mhani?” ni kun i kambeleni ni ta va kahle himphfuka nuna wa mina va lova hi 2000
Researcher	Laughing!
Participant	Va ku hita endla yini, ivi hi tekana va ya ni kambela ivi va tshama ti awara, na ti awara va hela va ku mhane mi hava nchumu, va ku layeni hi lowu I wunwe, ni ku tjoo! Ni khensa xikwembu hi lexi xa ha ni hlayisini maswi vona
Researcher	Uhhh!
Participant	Ni khensa xikwembu nuna wa mina I love khale vanwani lava va nga loveliwa na vona va fambe khale
Researcher	Va fambe khale, hi kuk ava nga ti hlayisi
Participant	Va fambe hinkwavo vanhu lava aka ha ri na munhu ani. Mina ni chava xinwe xikwembu lexi xi nga ni hlayisa ka hinkwaswo, ani se hlangana na swa misava leyi, xikwembu xaha ni veke kahle.leswi ni mi hlamuselaku I mavabyi lama ma ni hambanyisaku na Noel and ani ma tivi ku mahuma kwini, ni vula swi sukela ka munhu wa mina la nga ndzeni.
Researcher	And ma swi vona loko nwina mo ka mi nga ri kona vamakwenu wa yena swi tava tikela ku sala va nwu hlayisa

Participant	Haa! Va nge nwu koti, xikwembu that is why xi ni ngetela masiku yak u hanya nwana loyi va nge nwu koti, va nge nwu koti nwana loyi, nay a loyi anga vukatini Noel ange nwu koti.ma swi vona ?, ani tivi sesi wa yena loko alo hanya kumbe sweswi...sesi wa yena loyi anga lova aza aku ka mhani, vanhu lavanga fa ava
	Iamuleli hiku buti wa nwina lava nga lova and Noel buti wa nwina lavanga lova ava mi lava ngopfu nwina mhani, Noel sweswi ava ta famba hinkwako va nghena na le Zimbabwe va tshungurisa Noel, ka mhani why loko kuriku I munhu loyi anga loya Noel alo yini kuka anga fangi kuvula sesi wa yena, aku Noel musi mhani I xanisa nwina musi. Niku “ na ku twa nwananga mara hiku rifu ari vuli, I fambini ani siya iva niku vanhu lava nga fa ava voni na yena I lovini akha a rilela makwenu wa yena
Researcher	Uhhm
Participant	I hava na ndhawu na sweswi ani tivi ku anga swi endlisa ku yini, ni the niku nwananga vanhu lavanga fa ava swi voni, loko ava lwela vanhu lava nga misaveni leswi I vulavurisaku swona ava ta nwu lwela Noel. Hi leswo ava lweli loko va famba va fambini
Researcher	Mara mo khensa xikwembu ku loko ku va ku ri na kwele vuxakeni ku va aya hlayisiwa kona, I ndlela yinwani yo kota ku vo nwu lwela ku a kota ku hlayiseka ani mi vulavula hi kuna va mankhelwani ami kumani
Participant	Ava ha ni lavi ni tshama kwala kaya
Researcher	Maswi vona ku
Participant	Aniku vani rhandza kasi ava ni rhandzi,se na va chava na sweswi, ho xewetana ntsena mara na chava ku ya ama kaya ka vona and vona va swi lava mina ana ha swilavi ku ya amakaya ya vona, ava tini sweswi loko Noel vuyini va tlhela va lava ku vuyelelana ka mina mara mha na ha va lavi na chava
Researcher	Uhhh!

Participant	Va ni kombe rirhandzu ro ka ri nga ri kahle, ni ku wena hosi I ta ni rivalela ni to xewetana na vona vanhu lava and ani va khomelangani ani va kwatelangani, noka ninga ha va koti hi leswi va nga ni komba swona va tlhela nwana wa vona wunwani a vulavula aku ilo loya nwana wa wena, mufana nkulukumba loko o huma a ni ta mi komba ni ku mufana loyi anga .....
Researcher	Se hi maritu manwana va ringeta k uvula ku hinwina mi loyaku?
Participant	Ehh! Hi mina ni nga loya nwana wa mina, se ni twa ni khensa xikwembu hi ku ani byi tivi na vuloyi ku va endlisa ku yini.ni twa ku loko I khongela vata ku pumba na vuloyi,va ta ku endla mihlolo leyi hinkwayo na yesu va nwu endle sweswo
Researcher	Va nwu endle sweswo
Participant	Se ni twa ni khensa mina hiku ani mina no tiva ku hosi-hosi loko ri xini ni khani khongela kwala kaya ka mina na vana va mina, a n'angeni ani ngheni mina no mkhidzama hi matsolo, ani lavi kuta mi hembel hambu swilo swa Noel ani zangi niya nghena a n'angeni ni kun i lava ku tiva ku mavabyi lama ma huma kwini
Researcher	Ku ma huma kwini.
Participant	Ayo tekiwa hi kokwani wa yena vaya nwu tshungurisa a n'angeni mina ani yangi na ku ya
Researcher	Hey....!livi swi nga nwu pfuni na ku nwi pfuna
Participant	Haa! Swi nga tirhi ni va nyiketini ni ku hiyaloye mi ngatoku ni ala na yena, mara swi nga tirhi ivi va ku teka nwana wa wena ani ku kumbexana. Ivi se ni tlha ni tlhveka na xi bedlhele ni kha niya, .se ani tivi kuri papa lavaya va nga va nwu nyikini swo hlamba naaa?
Researcher	Hi vahi, lava leee xibedlhele?
Participant	Ehh!
Researcher	Vatava va nwu nyikini ni ta fika nimi chekela mundzuku.
Participant	Kumbe ni nga mi nyika xikhiya ntsena
Researcher	Xikhiya xa yini?
Participant	Xa lexiya xa lokhari ya yena



Researcher	I siye xikhiya xa lokhari?
Participant	Ehh! Yi khiyiwini
Researcher	Ehh! Xikhiya mi nga ni nyika nita vuya ni ta famba na xona ni ta nwu nyika mundzuku
Participant	Ehhh!
Researcher	Hay ni khensini ka mhani
Participant	Ehh! Na mina na khensa, ni khensini ni khensa loko mita mi ta ni seketela
Researcher	Ehh!
Participant	Ehh mara ka vanhu lava mi kumekaku mi ta ni seketela .....mhani wa munti lowu wa yindlu ya deke hi yena a kotaku kuni seketela, ni ku phela vanhu hinkwenu ama ha ni lavi, aku "mina minga katsi na mina"aku na swi tiva ku nwana wa wena ango tiendlisa o vabya.
Researcher	Ehh vakota ku twisisa xiyimo, vanhu ani vanwani loko va nga swi tivi swa mavabyi lama va twa ingaku oti endilsa
Participant	Ava nga swi tivi na vona mukhalabya vala va kwala ava nga swi tivihhi kona va swi vona ku nwana wa lahaya muntini lowuya a ngo tiendlisa. Siku rinwani loko se ni nwu yisini avuxakeni a ti pfalela la ndlwini anga humeli na le handle, aya huma hi siku ra vumbirhi a ha ti pfalerini vhiki hinkwaro ati pfalerini, swilu hinkwaswo a swi endlela la ndlwini la, a humesa a ya cukumeta miku duu ni ku yaaa!ive loko xibedlhele xinwu tekini aya pfaleriwa le, mina ani larise swinwani mhane,nwansati wa lahaya mintini luwa ani mi byela hi wona va ku mina ani ku mi vabya Aids,se ni ku "hay...!ka mhani loko kova nwina kuri nwana wa nwina ati pfalela la ndlwini vkiki hinkwaro minga va njhani?" se loko ano karhiha, ma swi vona ku ku amukela yesu swi kahle?
Researcher	Swi kahle.

Participant	I nge ni khomisane na mhani loyi ni ku mhani loyi iri mina ani kahle, and I nkarhi lowu aswa ha dumini ku loko munhu aku endlela leswiya nwu reporti kambe ni swi teka hi moya wa kahle, hiku avo gungula va ku ani kahle niku hay... VA vona ni cincini, ma swi vona ku sweswi ni kahle njhani? Ni kun i twa ni ri kahle hiku ani la anga kona I hlayisekini
Researcher	I hlayisekini swinene
Participant	Maswi vona? Uhh! na khensa mhani
Researcher	Hay ku khensa mina mhani loko mi ta va mini pfulekerini ani hina ho famba hi kha hi lavisisa
Participant	hiswona



## Annexure F: Language editing

# Between lines editing

Leatitia Romero  
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(BA HONS)

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15 September 2019

To whom it may concern:

I hereby confirm that I have edited the dissertation entitled: “The Lived Experience of Family Members Caring for a Relative with Mental Illness”. Any amendments introduced by the author hereafter are not covered by this confirmation. The author ultimately decided whether to accept or decline any recommendations made by the editor, and it remains the author’s responsibility at all times to confirm the accuracy and originality of the completed work.

Leatitia Romero

(Electronically sent – no signature)

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### Affiliations

PEG: Professional Editors Group (ROM001)  
EASA: English Academy of South Africa  
SATI: South African Translators’ Institute (1003002)  
SfEP: Society for Editors and Proofreaders (15687)  
REASA: Research Ethics Committee Association of Southern Africa (104)



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